



November - December 2023 Full Insights Report
**The impact of neurological conditions on mental health & access
to specialists' appointments**

Brain & Spine
Foundation

THE
NEUROLOGICAL
ALLIANCE

COMMUNITY
FUND

About NeuroLifeNow

NeuroLifeNow was launched in January 2021, enabling people to meaningfully share their daily realities of living with a neurological condition(s) to inform positive change to policy and services.

NeuroLifeNow aims to capture real-time evidence, at scale, from people across the UK. Working directly with people affected by neurological conditions through an innovative web-based technology has been developed and continues to evolve, along with ways for people that do not have access to digital technology to share their daily realities.

Through NeuroLifeNow people share how neurological condition(s) have impacted every aspect of their life. From accessing treatment, care, and support, to home life, work and finances. People do so with confidence that what they share is treated sensitively and handled securely.

Foreword

The final survey of 2023 for NeuroLifeNow was our most successful yet, thanks to the overwhelming participation of our growing community. More than 600 people responded, representing over 100 different neurological conditions. This level of engagement underscores the importance of the work we're doing and provides a strong foundation for amplifying the voices of those living with neurological conditions.

The Power of Community

The NeuroLifeNow community continues to grow, and with that growth comes increased strength and influence. By sharing your experiences, you're helping to shape a future where people with neurological conditions have a louder, more unified voice. This is crucial in advocating for better healthcare services, improved policies, and greater public awareness. As we look ahead, your participation enables us to draw clearer insights from the data and speak with even greater authority about the challenges and needs of those with neurological conditions.

Complex Health Challenges

One of the most striking findings from the survey was the complexity many people face in managing their health. Nearly half of the respondents (48%) reported having more than one neurological condition, and 71% said they had an additional non-neurological condition. This means that a significant number of people are juggling multiple health concerns, which can complicate their healthcare journeys. The healthcare system often struggles to meet the needs of these individuals, indicating a gap that must be addressed.

Positive Healthcare Experiences

Despite these challenges, there are reasons for optimism. Four in 10 respondents (41%) reported a positive experience with health and care services, and more than seven in 10 (72%) found their health appointments helpful. This shows that when people can access healthcare, they often find it beneficial.

However, those with multiple neurological conditions were less likely to have a positive experience, suggesting that the healthcare system might not be adequately equipped to handle complex cases. This is an area where improvement is needed.

Bridging the Gap

The fact that so many people found their health appointments helpful is encouraging. It indicates that healthcare providers are making a positive impact, even if there's still room for improvement. Our goal at NeuroLifeNow is to ensure that these positive experiences become universal, regardless of where people live or how complex their health needs are. By focusing on the core questions that matter to you, we aim to improve your experience with our platform and, by extension, contribute to the broader effort to enhance healthcare services for people with neurological conditions.

Thank You

Your experiences have been used to inform neurology transformation programmes nationally, influence major Government health initiatives and influence healthcare practice.

As we close out 2023, we want to express our deepest gratitude to the thousands of people who have taken the time to respond to NeuroLifeNow this past year. Your insights and stories are invaluable in helping us understand the realities of living with neurological conditions. Together, we're building a community that can drive meaningful change and make a real difference in the lives of those affected by neurological conditions.

Thank you for your support, and we look forward to continuing this journey with you in the coming year.

Marc Smith, CEO Brain and Spine Foundation

Georgina Carr, CEO, The Neurological Alliance (England)

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Key Findings

672 responses were received in November to December 2023. **114 conditions were represented**, and 48% reported living with more than one condition.

41% of respondents had good or very good experience of health and care in November and December 2023. **People reporting multiple conditions were less likely to say that their overall experience of healthcare was good or very good**, compared to those with one condition.

71% of people reported living with a (non-neurological) condition in addition to their neurological condition.

More than half (52%) of respondents said they were feeling anxious. Just 18% said they felt well supported.

37% of people said their mental health needs were not being met at all. People living with multiple neurological conditions were more likely to report this.

64% of people had a healthcare appointment in the past 8 weeks. 7% had more than 5 appointments in just 8 weeks.

72% found their appointments helpful. A third (33%) of appointments were held with a GP, 21% with a specialist nurse.

The **majority (78%) of appointments** were held **face to face**.

Overall experience of health & care

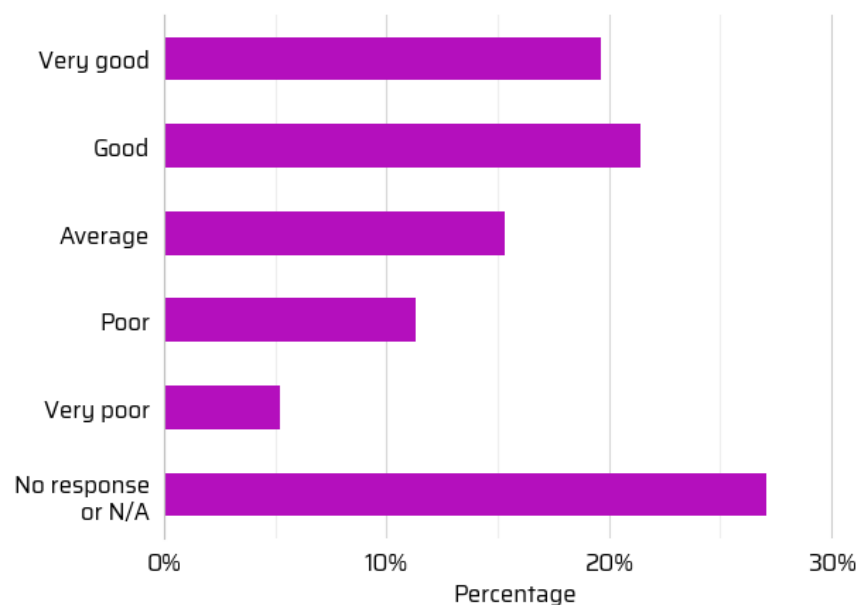


Figure 1: Overall experience of health & care.

Table 1: Overall experience of health & care.

Experience	Respondents	Percentage
Very good	132	19.64
Good	144	21.43
Average	103	15.33
Poor	76	11.31
Very poor	35	5.21
No response or N/A	182	27.08

Overall experience of healthcare by whether diagnosed with multiple neurological conditions.

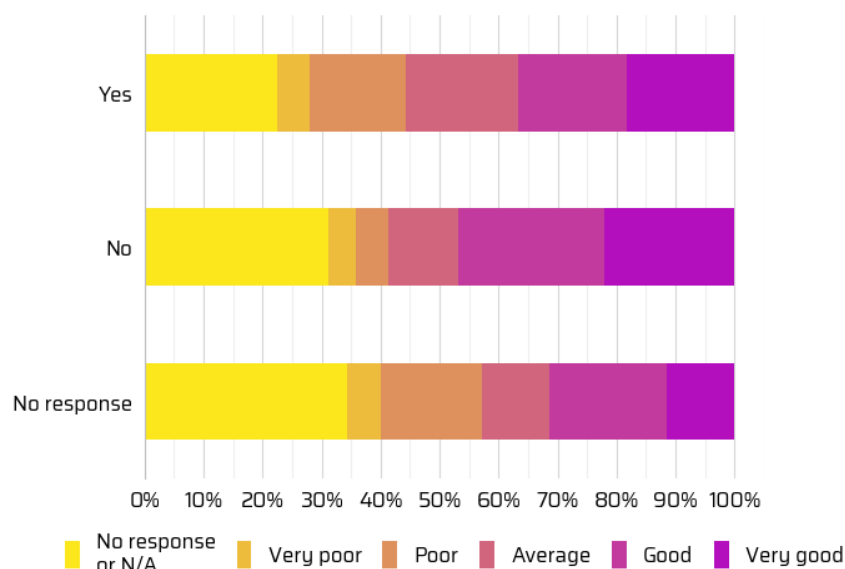


Figure 2: Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

Table 2: Overall experience of healthcare, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Experience	Respondents	Percentage
Yes	Very good	59	18.15
	Good	60	18.46
	Average	62	19.08
	Poor	53	16.31
	Very poor	18	5.54
	No response or N/A	73	22.46
No	Very good	69	22.12
	Good	77	24.68
	Average	37	11.86
	Poor	17	5.45

No response	Very poor	15	4.81
	No response or N/A	97	31.09
	Very good	4	11.43
	Good	7	20.0
	Average	4	11.43
	Poor	6	17.14
	Very poor	2	5.71
	No response or N/A	12	34.29

Overall experience of healthcare by age group.

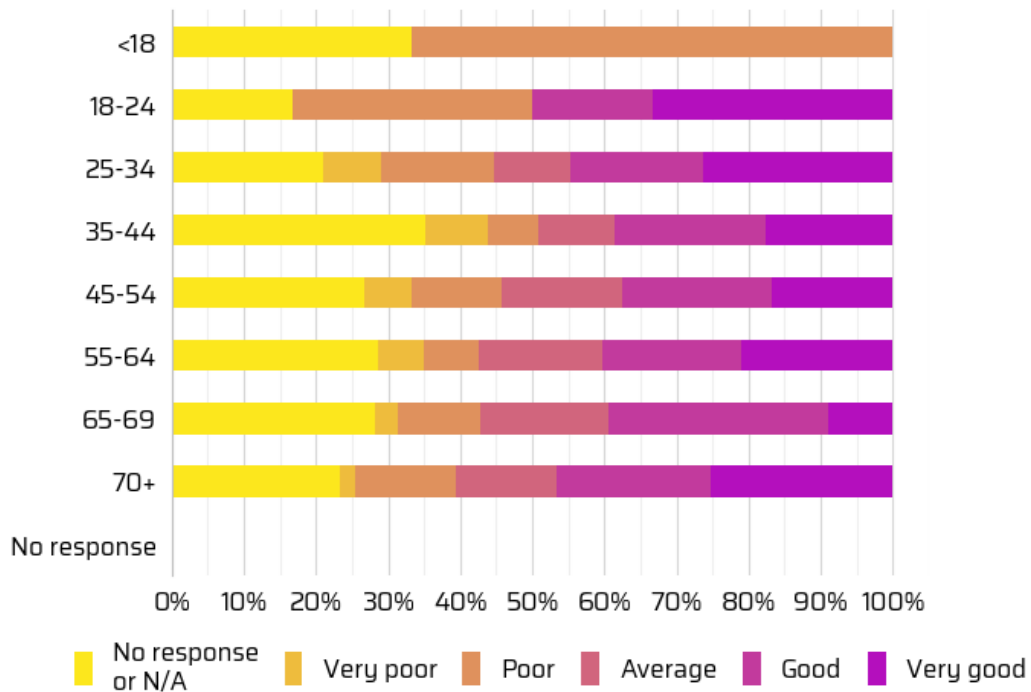


Figure 3: Overall experience of healthcare, broken down by age group.

Table 3: Overall experience of healthcare, broken down by age group.

Age	Experience	Respondents	Percentage
<18	Very good	0	0.0
	Good	0	0.0

	Average	0	0.0
	Poor	2	66.67
	Very poor	0	0.0
	No response or N/A	1	33.33
18-24	Very good	2	33.33
	Good	1	16.67
	Average	0	0.0
	Poor	2	33.33
	Very poor	0	0.0
	No response or N/A	1	16.67
25-34	Very good	10	26.32
	Good	7	18.42
	Average	4	10.53
	Poor	6	15.79
	Very poor	3	7.89
	No response or N/A	8	21.05
35-44	Very good	10	17.54
	Good	12	21.05
	Average	6	10.53
	Poor	4	7.02
	Very poor	5	8.77
	No response or N/A	20	35.09
45-54	Very good	20	16.67
	Good	25	20.83
	Average	20	16.67

	Poor	15	12.5
	Very poor	8	6.67
	No response or N/A	32	26.67
	Very good	44	21.05
	Good	40	19.14
	Average	36	17.22
55-64	Poor	16	7.66
	Very poor	13	6.22
	No response or N/A	60	28.71
	Very good	8	8.99
	Good	27	30.34
	Average	16	17.98
65-69	Poor	10	11.24
	Very poor	3	3.37
	No response or N/A	25	28.09
	Very good	38	25.33
	Good	32	21.33
	Average	21	14.0
70+	Poor	21	14.0
	Very poor	3	2.0
	No response or N/A	35	23.33
	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
No response	Poor	0	0.0

Very poor	0	0.0
No response or N/A	0	0.0

Overall experience of healthcare by gender.

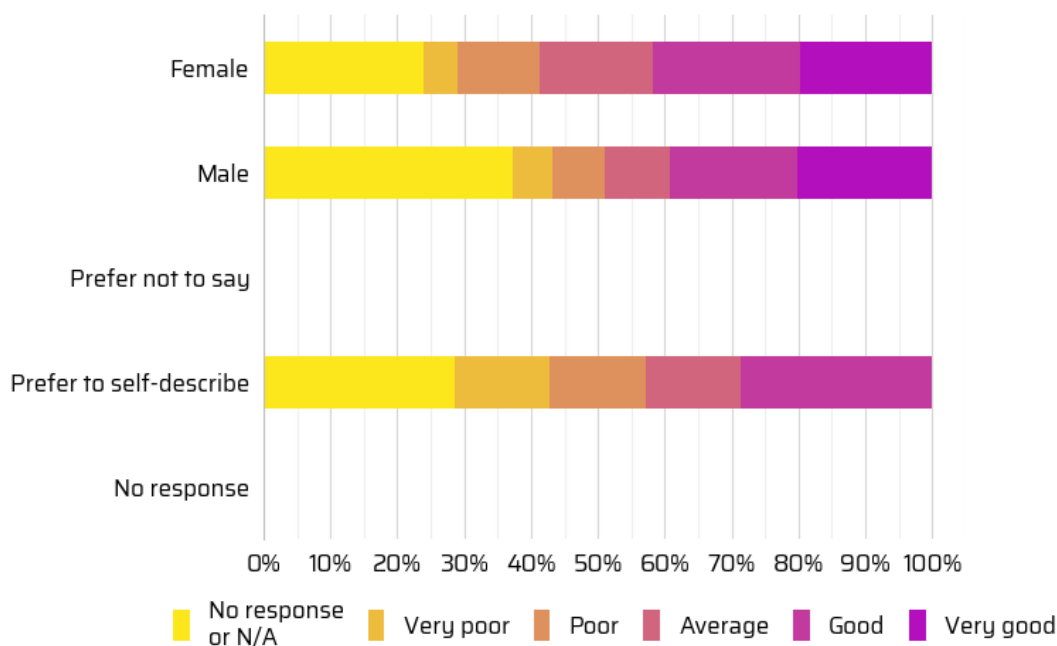


Figure 4: Overall experience of healthcare, broken down by gender.

Table 4: Overall experience of healthcare, broken down by gender.

Gender	Experience	Respondents	Percentage
Female	Very good	101	19.73
	Good	113	22.07
	Average	87	16.99
	Poor	63	12.3
	Very poor	25	4.88
	No response or N/A	123	24.02
Male	Very good	31	20.26
	Good	29	18.95

	Average	15	9.8
	Poor	12	7.84
	Very poor	9	5.88
	No response or N/A	57	37.25
Prefer not to say	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	0	0.0
Prefer to self-describe	Very good	0	0.0
	Good	2	28.57
	Average	1	14.29
	Poor	1	14.29
	Very poor	1	14.29
	No response or N/A	2	28.57
No response	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	0	0.0

Overall experience of healthcare by employment status.

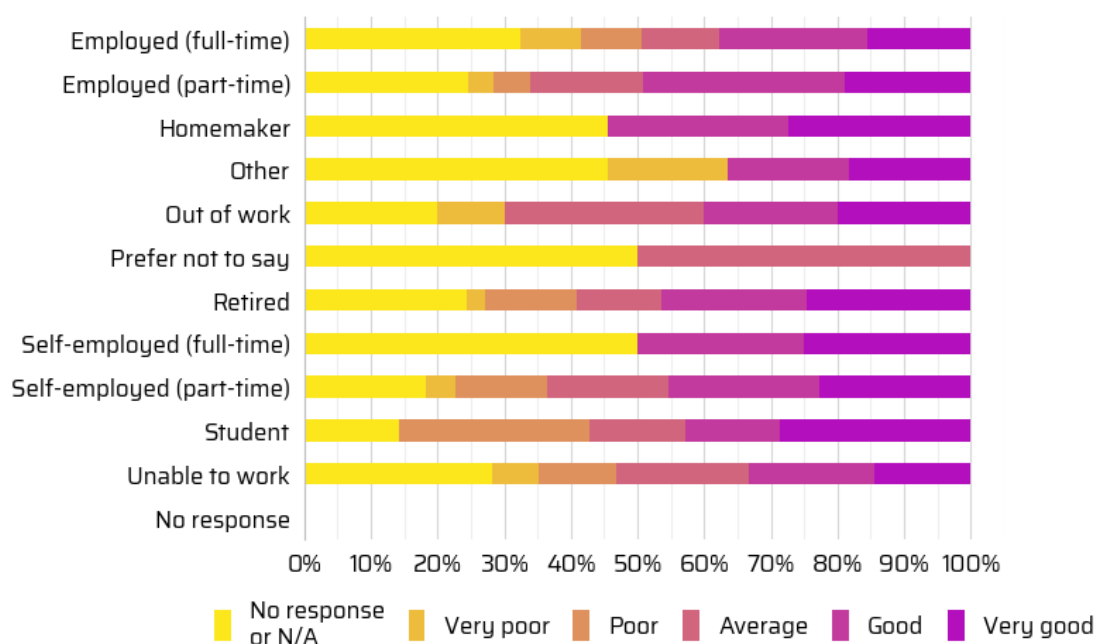


Figure 5: Overall experience of healthcare, broken down by employment status.

Table 5: Overall experience of healthcare, broken down by employment status.

Employment status	Experience	Respondents	Percentage
Employed (full-time)	Very good	12	15.58
	Good	17	22.08
	Average	9	11.69
	Poor	7	9.09
	Very poor	7	9.09
	No response or N/A	25	32.47
Employed (part-time)	Very good	10	18.87
	Good	16	30.19
	Average	9	16.98
	Poor	3	5.66
	Very poor	2	3.77

	No response or N/A	13	24.53
Homemaker	Very good	3	27.27
	Good	3	27.27
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	5	45.45
Other	Very good	2	18.18
	Good	2	18.18
	Average	0	0.0
	Poor	0	0.0
	Very poor	2	18.18
	No response or N/A	5	45.45
Out of work	Very good	2	20.0
	Good	2	20.0
	Average	3	30.0
	Poor	0	0.0
	Very poor	1	10.0
	No response or N/A	2	20.0
Prefer not to say	Very good	0	0.0
	Good	0	0.0
	Average	1	50.0
	Poor	0	0.0
	Very poor	0	0.0

	No response or N/A	1	50.0
Retired	Very good	64	24.71
	Good	56	21.62
	Average	33	12.74
	Poor	36	13.9
	Very poor	7	2.7
	No response or N/A	63	24.32
Self-employed (full-time)	Very good	1	25.0
	Good	1	25.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	2	50.0
Self-employed (part-time)	Very good	5	22.73
	Good	5	22.73
	Average	4	18.18
	Poor	3	13.64
	Very poor	1	4.55
	No response or N/A	4	18.18
Student	Very good	2	28.57
	Good	1	14.29
	Average	1	14.29
	Poor	2	28.57
	Very poor	0	0.0

	No response or N/A	1	14.29
Unable to work	Very good	31	14.35
	Good	41	18.98
	Average	43	19.91
	Poor	25	11.57
	Very poor	15	6.94
	No response or N/A	61	28.24
No response	Very good	0	0.0
	Good	0	0.0
	Average	0	0.0
	Poor	0	0.0
	Very poor	0	0.0
	No response or N/A	0	0.0

Overall experience of healthcare by number of dependents.

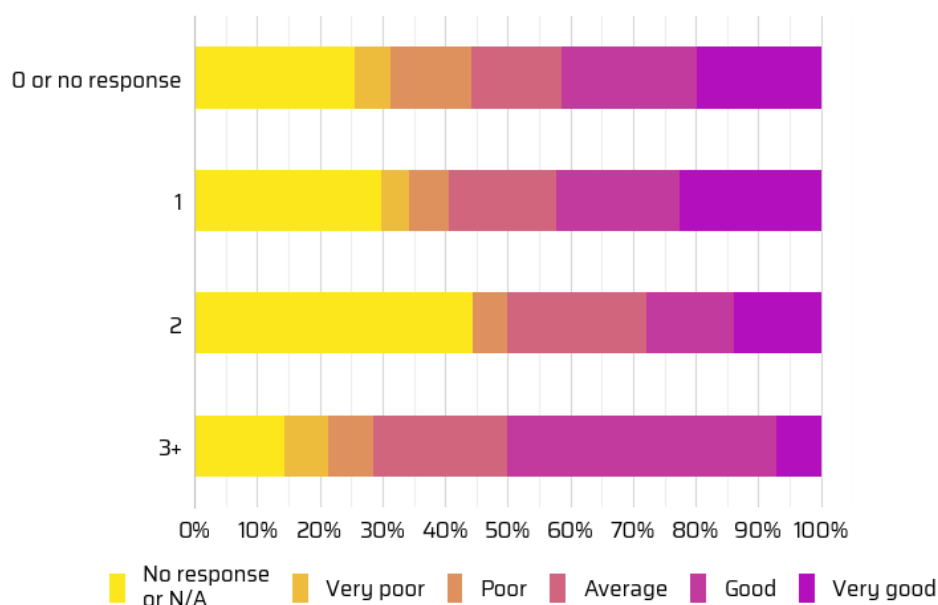


Figure 6: Overall experience of healthcare, broken down by number of dependents.

Table 6: Overall experience of healthcare, broken down by number of dependents.

Number of dependents	Experience	Respondents	Percentage
0 or no response	Very good	101	19.77
	Good	111	21.72
	Average	73	14.29
	Poor	66	12.92
	Very poor	29	5.68
	No response or N/A	131	25.64
1	Very good	25	22.52
	Good	22	19.82
	Average	19	17.12
	Poor	7	6.31
	Very poor	5	4.5

	No response or N/A	33	29.73
2	Very good	5	13.89
	Good	5	13.89
	Average	8	22.22
	Poor	2	5.56
	Very poor	0	0.0
	No response or N/A	16	44.44
3+	Very good	1	7.14
	Good	6	42.86
	Average	3	21.43
	Poor	1	7.14
	Very poor	1	7.14
	No response or N/A	2	14.29

Mental health

Current feelings

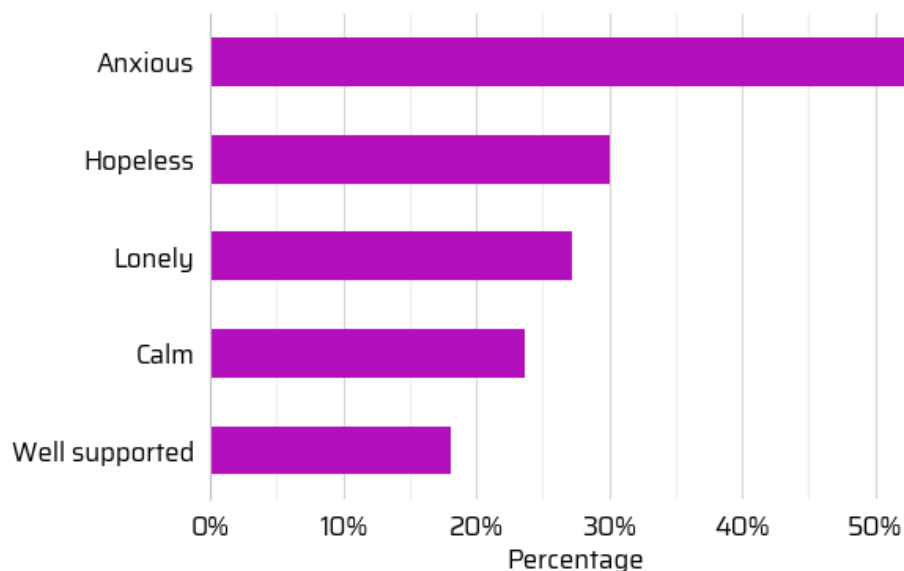


Figure 7: Feelings of the respondents at the time of the survey.

Table 7: Feelings of the respondents at the time of the survey.

Feelings	Respondents	Percentage
Anxious	352	52.38
Hopeless	202	30.06
Lonely	183	27.23
Calm	159	23.66
Well supported	122	18.15

Note: A single respondent may have selected multiple options for this question, so the total number of responses may not add up to the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of respondents.

Neurological conditions impact on quality of life

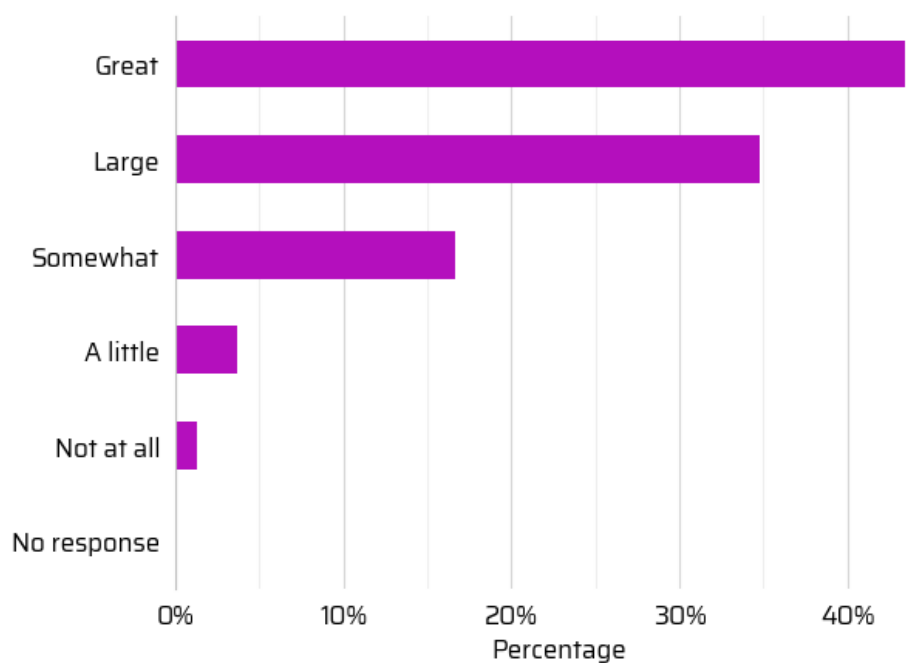


Figure 8 The extent to which neurological conditions affect quality of life.

Table 8 The extent to which neurological conditions affect quality of life.

Impact	Respondents	Percentage
Great	292	43.45
Large	234	34.82
Somewhat	112	16.67
A little	25	3.72
Not at all	9	1.34
No response	0	0.0

Extent mental health needs were met.

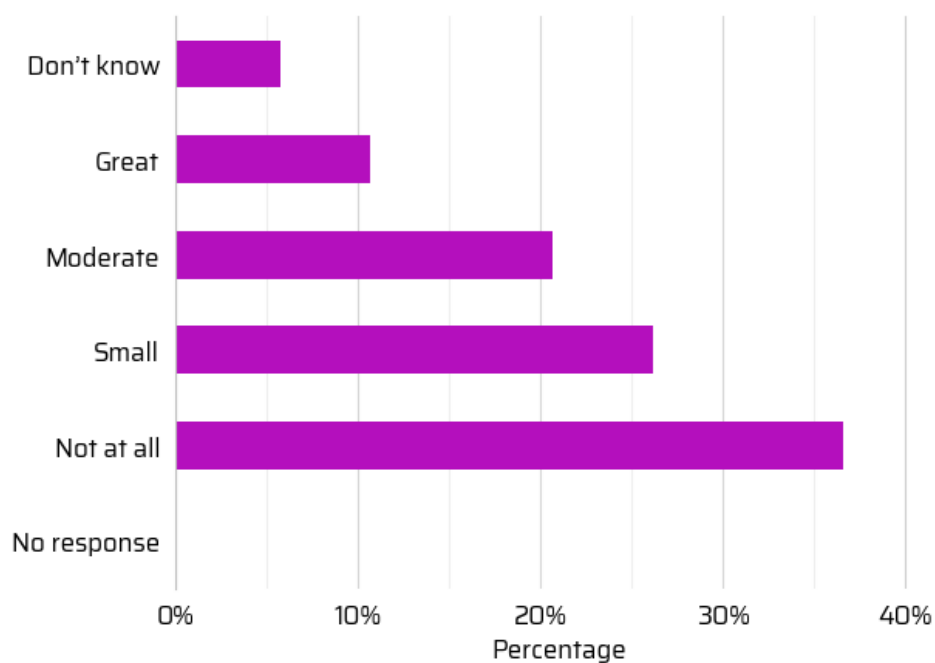


Figure 9: The extent to which respondents' mental health needs were met.

Table 9: The extent to which respondents' mental health needs were met.

Needs met	Respondents	Percentage
Don't know	39	5.8
Great	72	10.71
Moderate	139	20.68
Small	176	26.19
Not at all	246	36.61
No response	0	0.0

Extent mental health needs were met by whether diagnosed with multiple neurological conditions.

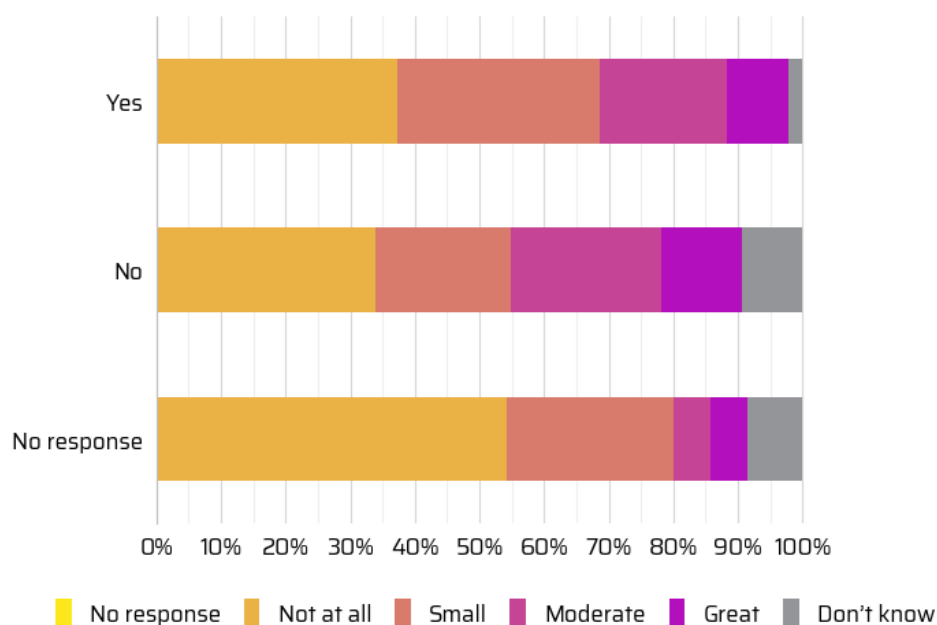


Figure 10: The extent to which respondents' mental health needs were met, broken down by whether diagnosed with multiple neurological conditions.

Table 10: The extent to which respondents' mental health needs were met, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Needs met	Respondents	Percentage
Yes	Don't know	7	2.15
	Great	31	9.54
	Moderate	64	19.69
	Small	102	31.38
	Not at all	121	37.23
	No response	0	0.0
No	Don't know	29	9.29
	Great	39	12.5
	Moderate	73	23.4

	Small	65	20.83
	Not at all	106	33.97
	No response	0	0.0
	Don't know	3	8.57
	Great	2	5.71
	Moderate	2	5.71
No response	Small	9	25.71
	Not at all	19	54.29
	No response	0	0.0

Extent mental health needs were met by age groups.

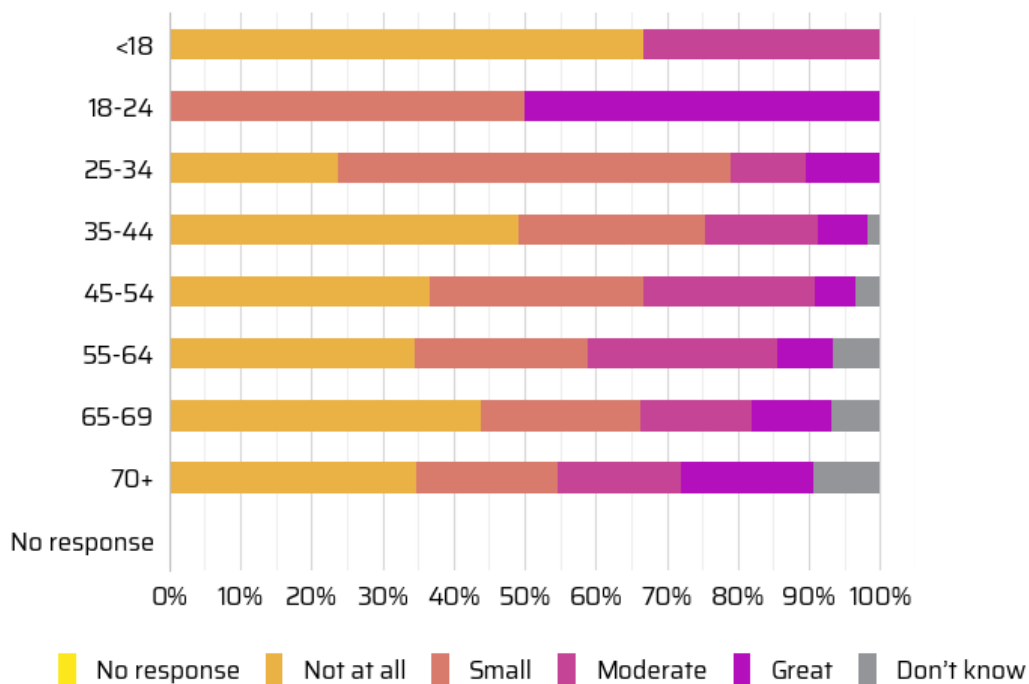


Figure 11 The extent to which respondents' mental health needs were met, broken down by age group

Table 11 The extent to which respondents' mental health needs were met, broken down by age group

Age	Needs met	Respondents	Percentage
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<18	Don't know	0	0.0
	Great	0	0.0
	Moderate	1	33.33
	Small	0	0.0
	Not at all	2	66.67
	No response	0	0.0
18-24	Don't know	0	0.0
	Great	3	50.0
	Moderate	0	0.0
	Small	3	50.0
	Not at all	0	0.0
	No response	0	0.0
25-34	Don't know	0	0.0
	Great	4	10.53
	Moderate	4	10.53
	Small	21	55.26
	Not at all	9	23.68
	No response	0	0.0
35-44	Don't know	1	1.75
	Great	4	7.02
	Moderate	9	15.79
	Small	15	26.32
	Not at all	28	49.12
	No response	0	0.0
45-54	Don't know	4	3.33
	Great	7	5.83
	Moderate	29	24.17
	Small	36	30.0

55-64	Not at all	44	36.67
	No response	0	0.0
	Don't know	14	6.7
	Great	16	7.66
	Moderate	56	26.79
	Small	51	24.4
	Not at all	72	34.45
	No response	0	0.0
65-69	Don't know	6	6.74
	Great	10	11.24
	Moderate	14	15.73
	Small	20	22.47
	Not at all	39	43.82
	No response	0	0.0
70+	Don't know	14	9.33
	Great	28	18.67
	Moderate	26	17.33
	Small	30	20.0
	Not at all	52	34.67
	No response	0	0.0
No response	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
	Small	0	0.0
	Not at all	0	0.0
	No response	0	0.0

Extent mental health needs were met by gender.

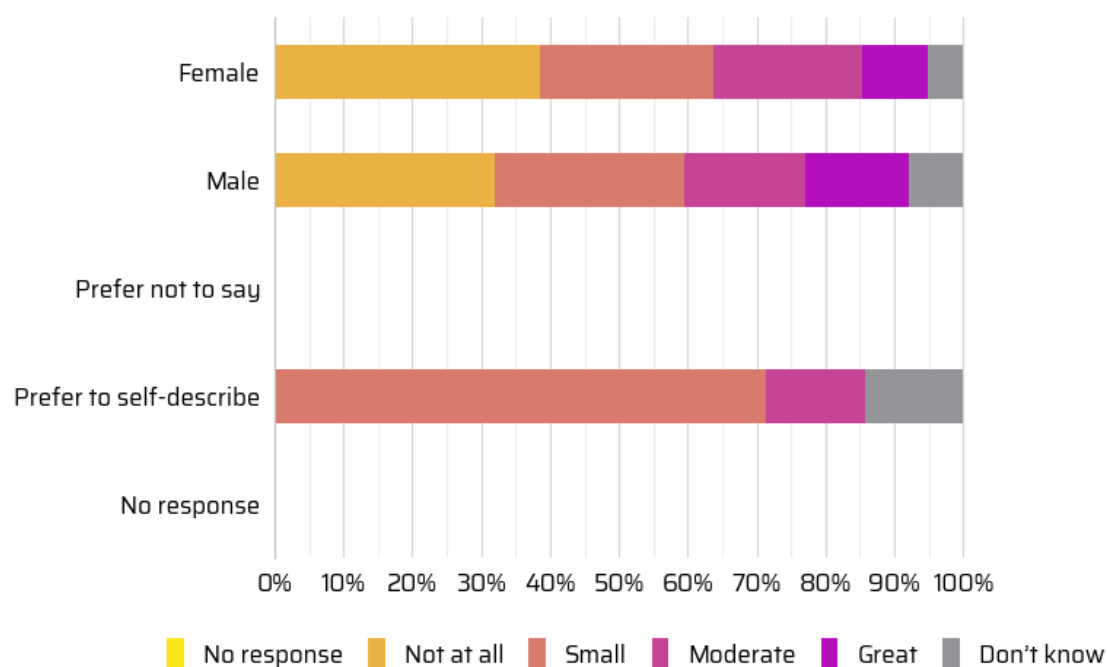


Figure 12: The extent to which respondents' mental health needs were met, broken down by gender.

Table 12: The extent to which respondents' mental health needs were met, broken down by gender.

Gender	Needs met	Respondents	Percentage
Female	Don't know	26	5.08
	Great	49	9.57
	Moderate	111	21.68
	Small	129	25.2
	Not at all	197	38.48
	No response	0	0.0
Male	Don't know	12	7.84
	Great	23	15.03
	Moderate	27	17.65
	Small	42	27.45
	Not at all	49	32.03
	No response	0	0.0

Prefer not to say	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
	Small	0	0.0
	Not at all	0	0.0
	No response	0	0.0
Prefer to self-describe	Don't know	1	14.29
	Great	0	0.0
	Moderate	1	14.29
	Small	5	71.43
	Not at all	0	0.0
	No response	0	0.0
No response	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
	Small	0	0.0
	Not at all	0	0.0
	No response	0	0.0

Extent mental health needs were met by employment status.

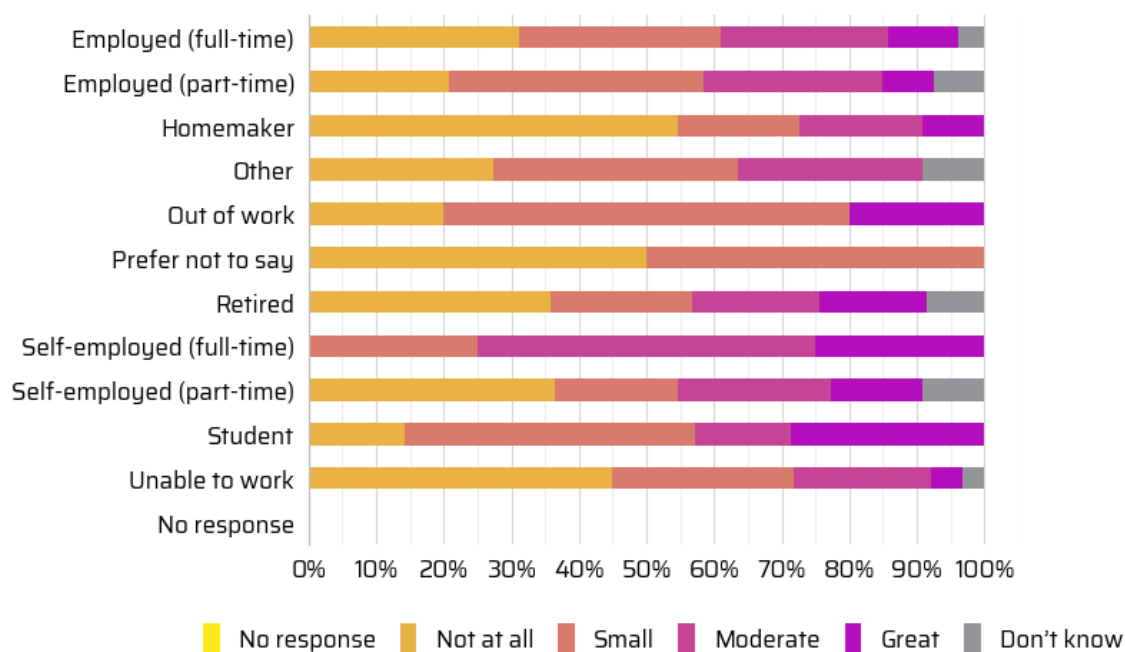


Figure 13: The extent to which respondents' mental health needs were met, broken down by employment status.

Table 13: The extent to which respondents' mental health needs were met, broken down by employment status.

Employment status	Needs met	Respondents	Percentage
Employed (full-time)	Don't know	3	3.9
	Great	8	10.39
	Moderate	19	24.68
	Small	23	29.87
	Not at all	24	31.17
	No response	0	0.0
Employed (part-time)	Don't know	4	7.55
	Great	4	7.55
	Moderate	14	26.42
	Small	20	37.74
	Not at all	11	20.75

Homemaker	No response	0	0.0
	Don't know	0	0.0
	Great	1	9.09
	Moderate	2	18.18
	Small	2	18.18
	Not at all	6	54.55
Other	No response	0	0.0
	Don't know	1	9.09
	Great	0	0.0
	Moderate	3	27.27
	Small	4	36.36
	Not at all	3	27.27
Out of work	No response	0	0.0
	Don't know	0	0.0
	Great	2	20.0
	Moderate	0	0.0
	Small	6	60.0
	Not at all	2	20.0
Prefer not to say	No response	0	0.0
	Don't know	0	0.0
	Great	0	0.0
	Moderate	0	0.0
	Small	1	50.0
	Not at all	1	50.0
Retired	No response	0	0.0
	Don't know	22	8.49
	Great	41	15.83
	Moderate	49	18.92

	Small	54	20.85
	Not at all	93	35.91
	No response	0	0.0
Self-employed (full-time)	Don't know	0	0.0
	Great	1	25.0
	Moderate	2	50.0
	Small	1	25.0
	Not at all	0	0.0
	No response	0	0.0
	Don't know	2	9.09
	Great	3	13.64
Self-employed (part-time)	Moderate	5	22.73
	Small	4	18.18
	Not at all	8	36.36
	No response	0	0.0
	Don't know	0	0.0
	Great	2	28.57
Student	Moderate	1	14.29
	Small	3	42.86
	Not at all	1	14.29
	No response	0	0.0
	Don't know	7	3.24
	Great	10	4.63
Unable to work	Moderate	44	20.37
	Small	58	26.85
	Not at all	97	44.91
	No response	0	0.0
	Don't know	0	0.0
	Great	1	25.0
No response	Don't know	0	0.0
	Great	1	25.0

Great	0	0.0
Moderate	0	0.0
Small	0	0.0
Not at all	0	0.0
No response	0	0.0

Extent mental health needs were met by number of dependents.

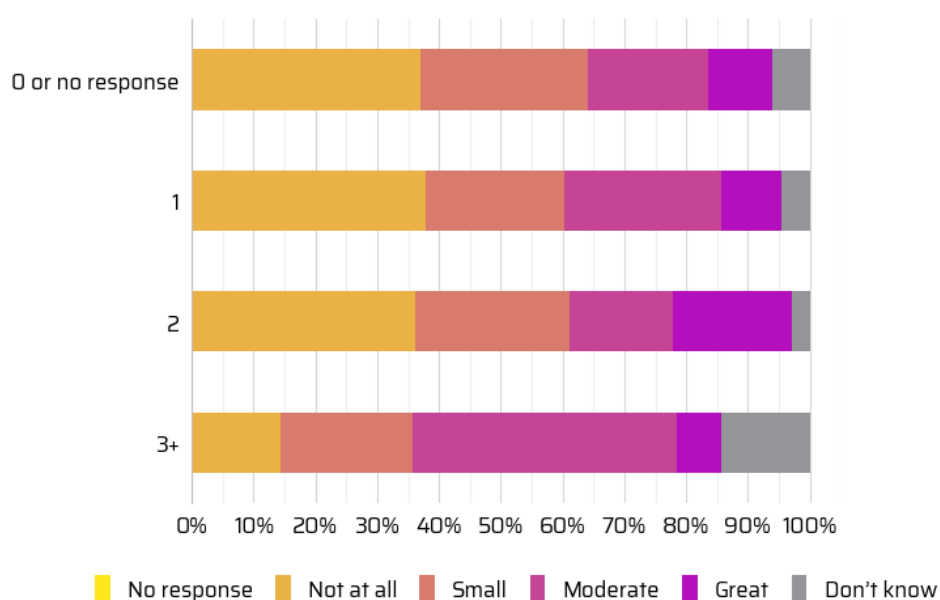


Figure 14: The extent to which respondents' mental health needs were met, broken down by number of dependents.

Table 14: The extent to which respondents' mental health needs were met, broken down by number of dependents.

Number of dependents	Needs met	Respondents	Percentage
0 or no response	Don't know	31	6.07
	Great	53	10.37
	Moderate	99	19.37
	Small	139	27.2

1	Not at all	189	36.99
	No response	0	0.0
	Don't know	5	4.5
	Great	11	9.91
	Moderate	28	25.23
	Small	25	22.52
	Not at all	42	37.84
2	No response	0	0.0
	Don't know	1	2.78
	Great	7	19.44
	Moderate	6	16.67
	Small	9	25.0
	Not at all	13	36.11
	No response	0	0.0
3+	Don't know	2	14.29
	Great	1	7.14
	Moderate	6	42.86
	Small	3	21.43
	Not at all	2	14.29
	No response	0	0.0

Medical appointments

Access to medical appointments in the last eight weeks

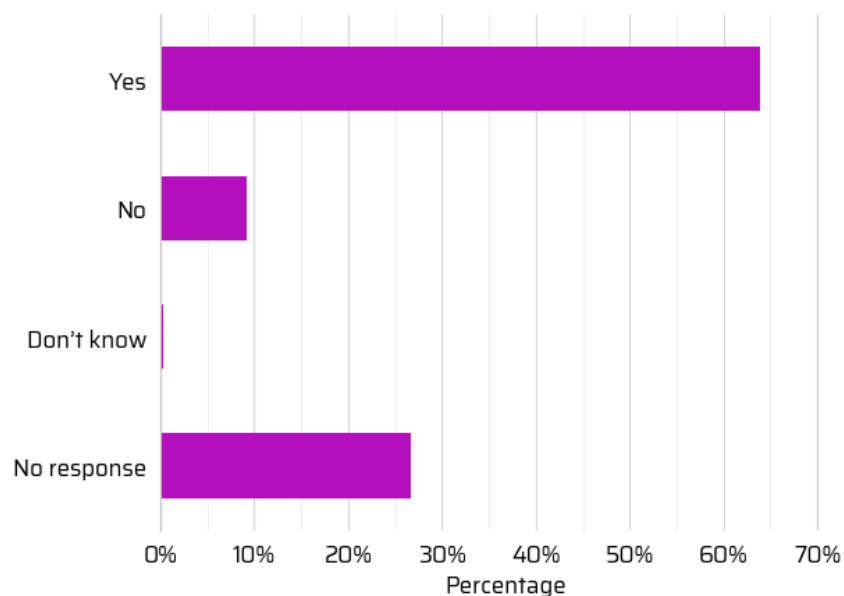


Figure 15: Access to medical appointments in the last eight weeks.

Table 15: Access to medical appointments in the last eight weeks.

Appointments	Respondents	Percentage
Yes	429	63.84
No	62	9.23
Don't know	2	0.3
No response	179	26.64

Number of medical appointments

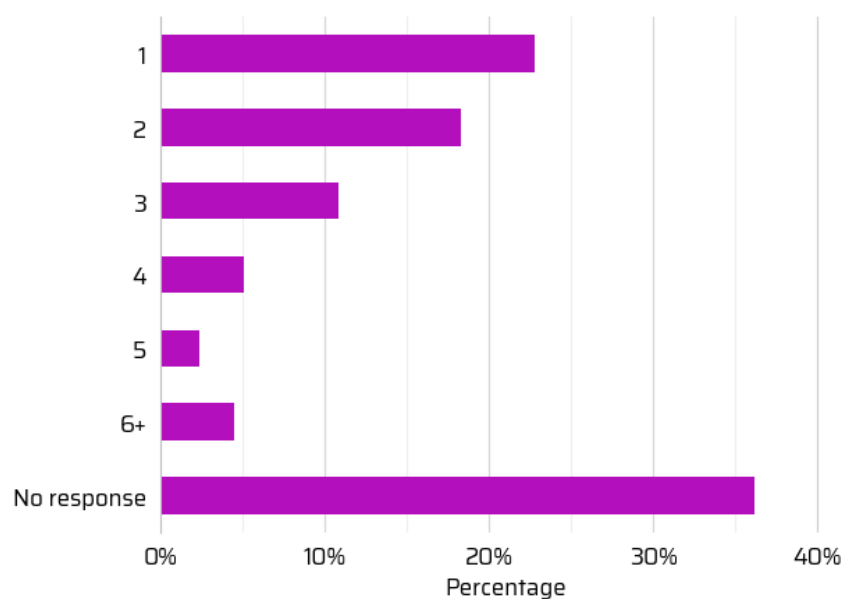


Figure 16: Number of medical appointments.

Table 16: Number of medical appointments.

Number of appointments	Respondents	Percentage
1	153	22.77
2	123	18.3
3	73	10.86
4	34	5.06
5	16	2.38
6+	30	4.46
No response	243	36.16

Helpfulness of medical appointments

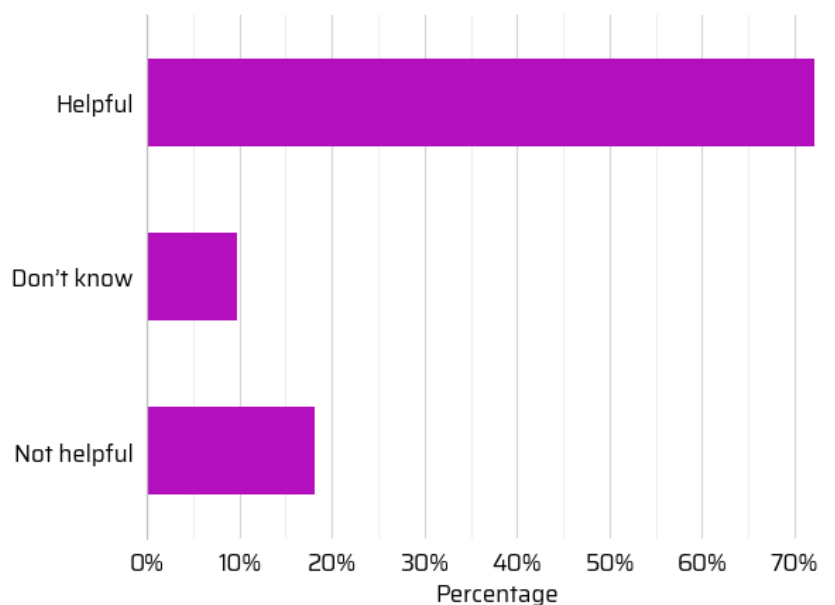


Figure 17: Helpfulness of medical appointments held in the last eight weeks.

Table 17: Helpfulness of medical appointments held in the last eight weeks.

Helpfulness	Respondents	Percentage
Helpful	768	72.11
Don't know	104	9.77
Not helpful	193	18.12

Note: Each respondent may have zero, one, or multiple appointments, so the total number of appointments may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of responses (i.e. appointments) to this question.

Specialty of medical appointments

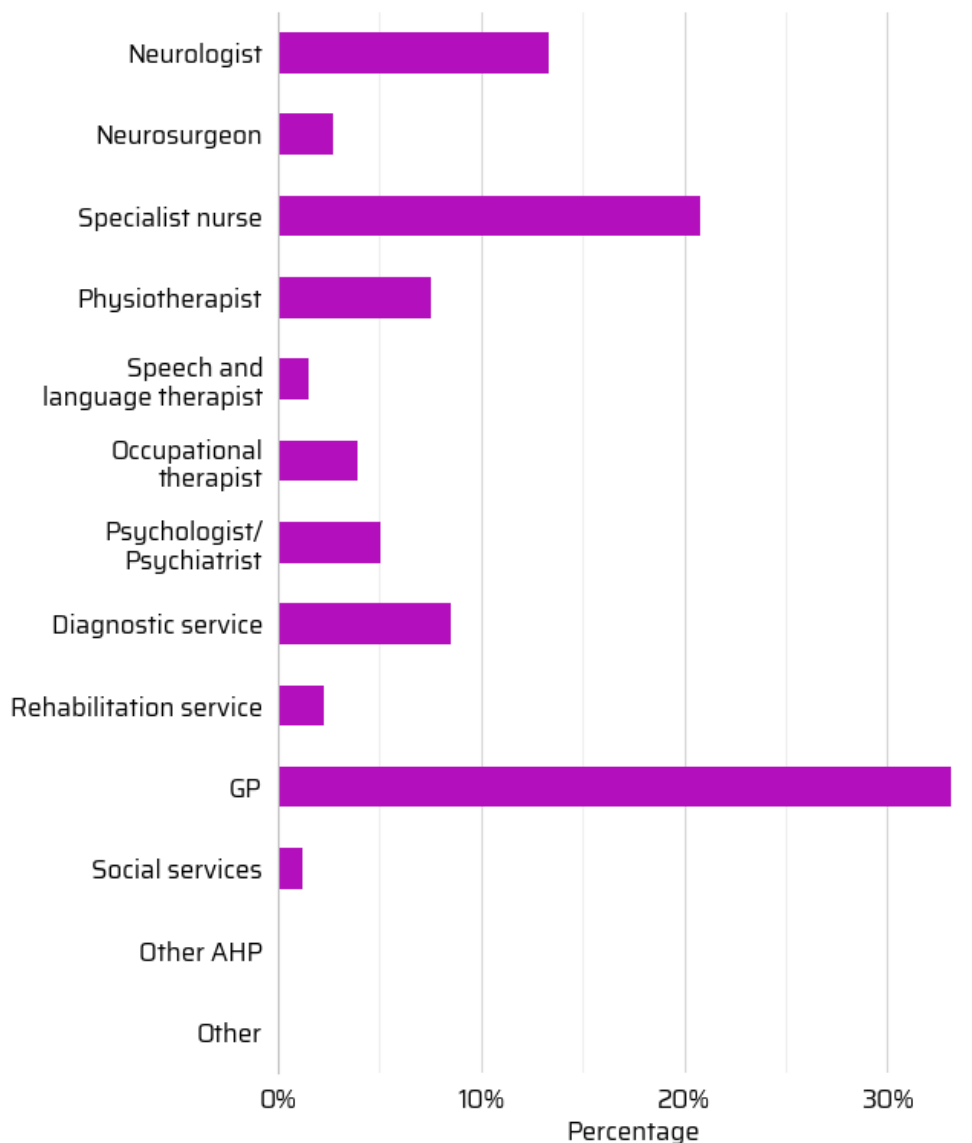


Figure 18: Speciality of the medical appointments held in the last eight weeks.

Table 18: Speciality of the medical appointments held in the last eight weeks.

Specialty	Respondents	Percentage
Neurologist	113	13.36
Neurosurgeon	23	2.72
Specialist nurse	176	20.8
Physiotherapist	64	7.57

Speech and language therapist	13	1.54
Occupational therapist	33	3.9
Psychologist/Psychiatrist	43	5.08
Diagnostic service	72	8.51
Rehabilitation service	19	2.25
GP	280	33.1
Social services	10	1.18
Other AHP	0	0.0
Other	0	0.0

Note: Each respondent may have zero, one, or multiple appointments, so the total number of appointments may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of responses (i.e. appointments) to this question.

Mode of medical appointments completed.

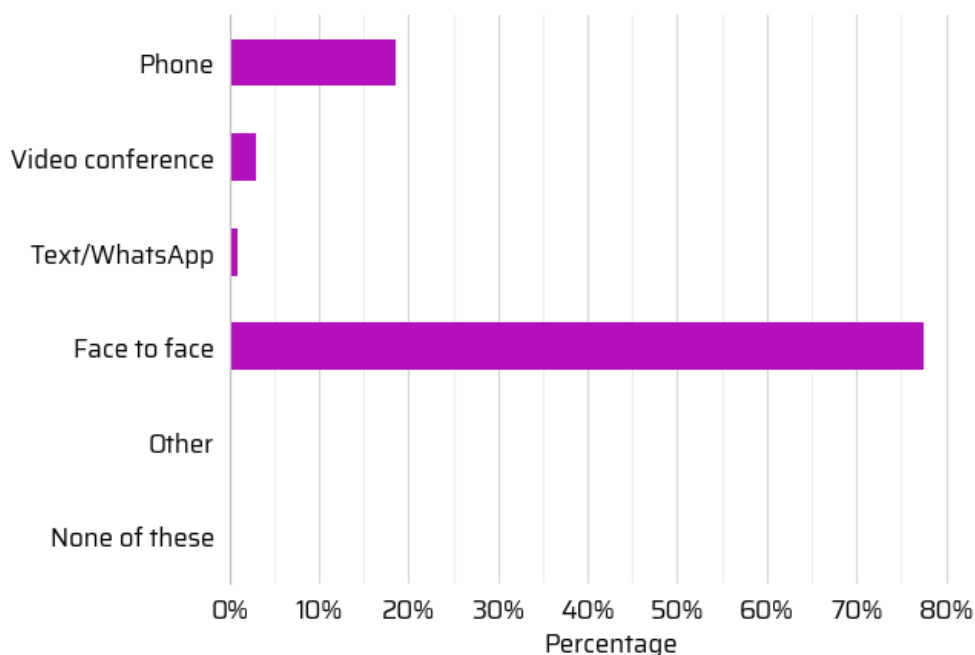


Figure 19: Mode of medical appointments completed in the last eight weeks.

Table 19: Mode of medical appointments completed in the last eight weeks.

Mode	Respondents	Percentage
Phone	193	18.56
Video conference	31	2.98
Text/WhatsApp	10	0.96
Face to face	806	77.5
Other	0	0.0
None of these	0	0.0

Note: Each respondent may have zero, one, or multiple appointments, so the total number of appointments may not match the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of responses (i.e. appointments) to this question.

Frequency NHS A&E/emergency services were sought.

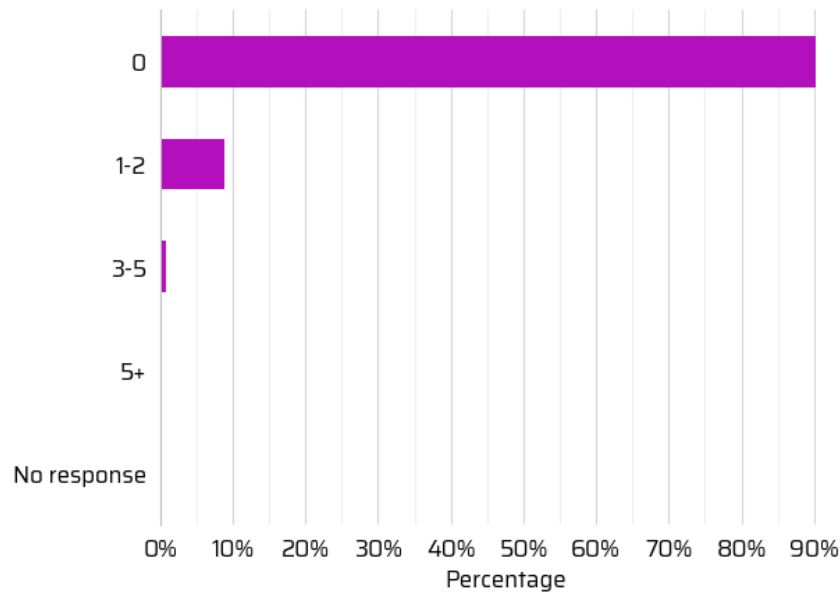


Figure 20: Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Table 20: Frequency that NHS A&E/emergency services were sought in the last eight weeks.

Frequency	Respondents	Percentage
0	606	90.18

1-2	59	8.78
3-5	6	0.89
5+	1	0.15
No response	0	0.0

Frequency NHS A&E/emergency services were sought by whether diagnosed with multiple neurological conditions.

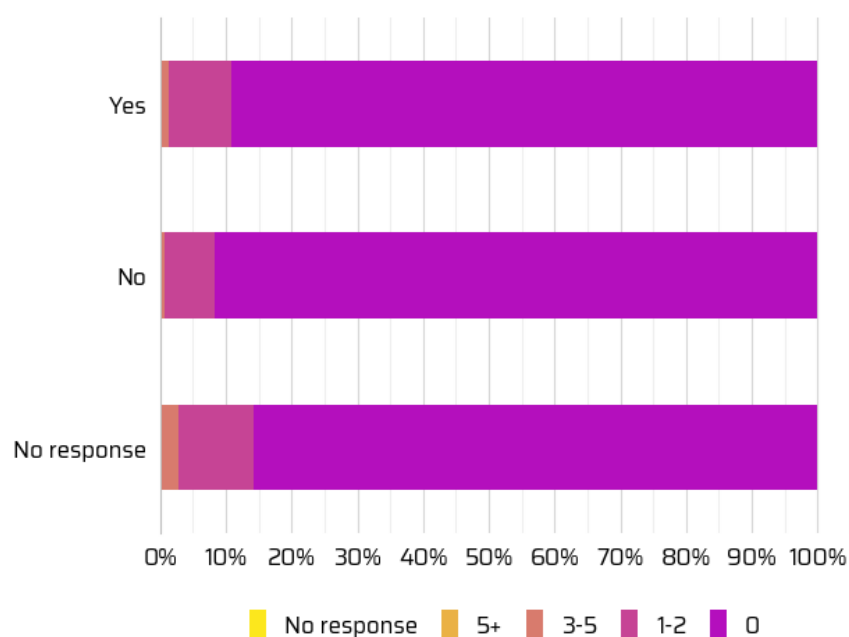


Figure 21: Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

Table 21: Frequency that NHS A&E/emergency services were sought, broken down by whether diagnosed with multiple neurological conditions.

Multiple neurological conditions	Frequency	Respondents	Percentage
Yes	0	290	89.23
	1-2	31	9.54
	3-5	3	0.92
	5+	1	0.15

	5+	1	0.31
	No response	0	0.0
No	0	286	91.67
	1-2	24	7.69
	3-5	2	0.64
	5+	0	0.0
	No response	0	0.0
No response	0	30	85.71
	1-2	4	11.43
	3-5	1	2.86
	5+	0	0.0
	No response	0	0.0

Frequency NHS A&E/emergency services were sought by age group.

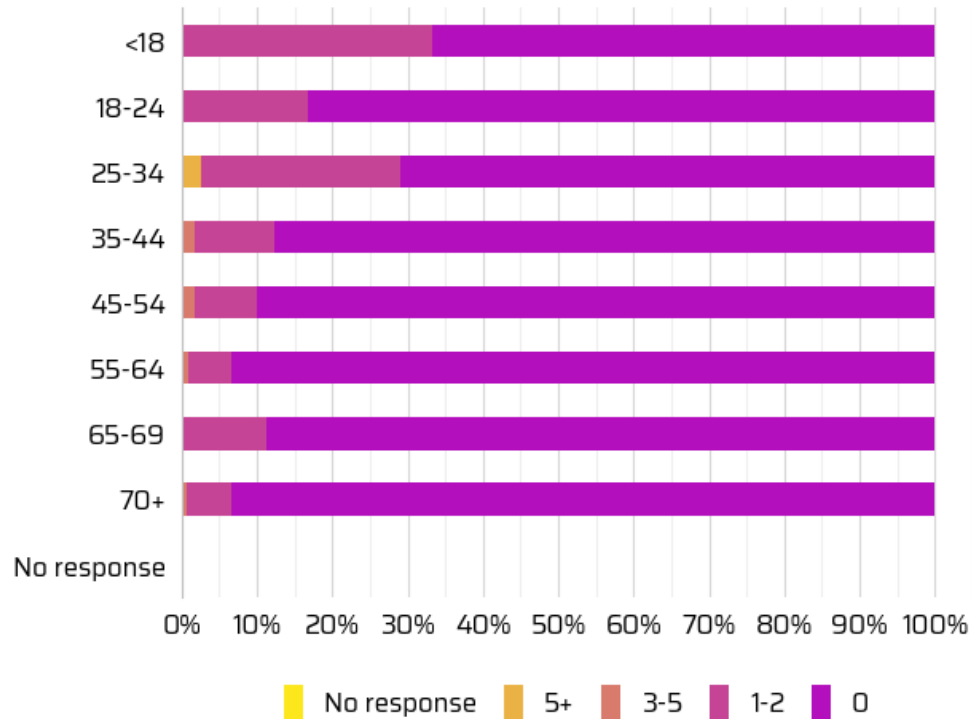


Figure 22: Frequency that NHS A&E/emergency services were sought, broken down by age group.

Table 22: Frequency that NHS A&E/emergency services were sought, broken down by age group.

Age	Frequency	Respondents	Percentage
<18	0	2	66.67
	1-2	1	33.33
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
18-24	0	5	83.33
	1-2	1	16.67
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0

25-34	0	27	71.05
	1-2	10	26.32
	3-5	0	0.0
	5+	1	2.63
	No response	0	0.0
35-44	0	50	87.72
	1-2	6	10.53
	3-5	1	1.75
	5+	0	0.0
	No response	0	0.0
45-54	0	108	90.0
	1-2	10	8.33
	3-5	2	1.67
	5+	0	0.0
	No response	0	0.0
55-64	0	195	93.3
	1-2	12	5.74
	3-5	2	0.96
	5+	0	0.0
	No response	0	0.0
65-69	0	79	88.76
	1-2	10	11.24
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
70+	0	140	93.33
	1-2	9	6.0
	3-5	1	0.67

	5+	0	0.0
	No response	0	0.0
No response	0	0	0.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0

Frequency NHS A&E/emergency services were sought by gender.

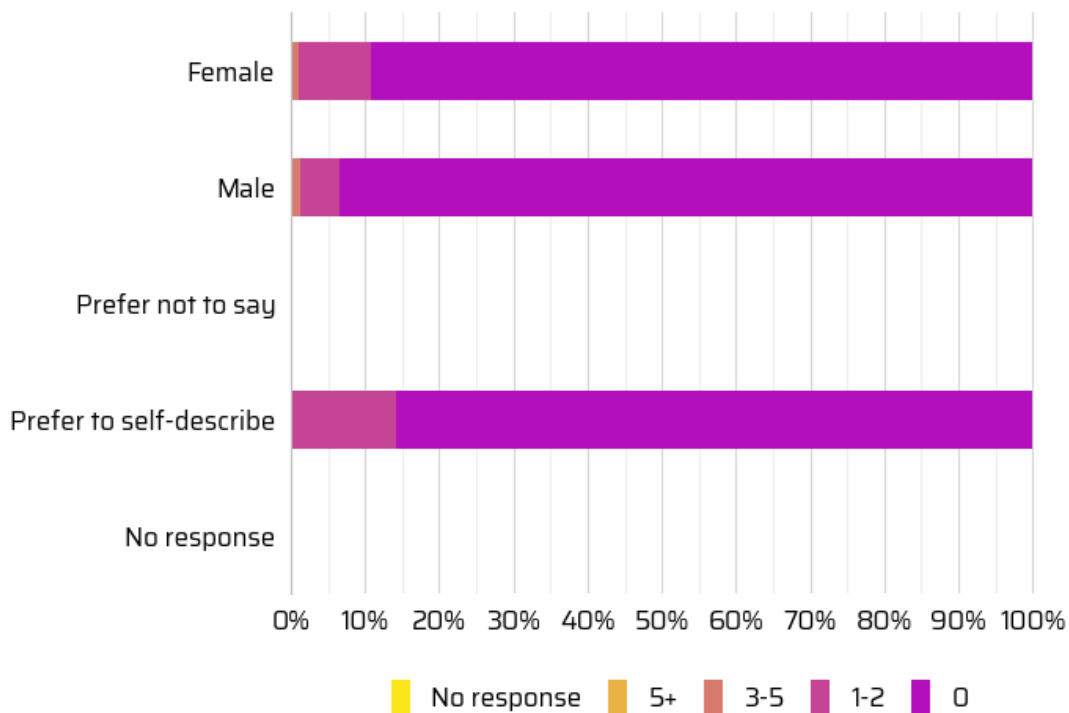


Figure 23: Frequency that NHS A&E/emergency services were sought, broken down by gender.

Table 23: Frequency that NHS A&E/emergency services were sought, broken down by gender.

Gender	Frequency	Respondents	Percentage
Female	0	457	89.26
	1-2	50	9.77

	3-5	4	0.78
	5+	1	0.2
	No response	0	0.0
	0	143	93.46
	1-2	8	5.23
Male	3-5	2	1.31
	5+	0	0.0
	No response	0	0.0
	0	0	0.0
	1-2	0	0.0
Prefer not to say	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	6	85.71
	1-2	1	14.29
Prefer to self-describe	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
	0	0	0.0
	1-2	0	0.0
No response	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0

Frequency NHS A&E/emergency services were sought by employment status.

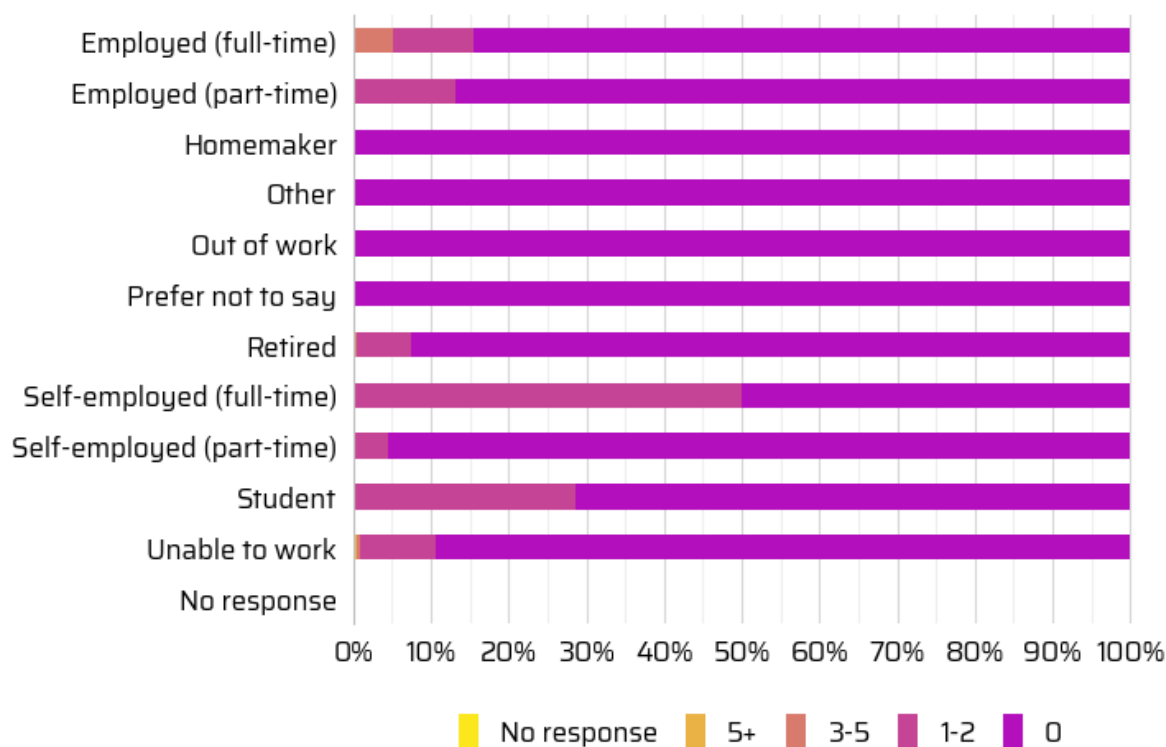


Figure 24: Frequency that NHS A&E/emergency services were sought, broken down by employment status.

Table 24: Frequency that NHS A&E/emergency services were sought, broken down by employment status.

Employment status	Frequency	Respondents	Percentage
Employed (full-time)	0	65	84.42
	1-2	8	10.39
	3-5	4	5.19
	5+	0	0.0
	No response	0	0.0
Employed (part-time)	0	46	86.79
	1-2	7	13.21
	3-5	0	0.0

	5+	0	0.0
	No response	0	0.0
Homemaker	0	11	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
Other	0	11	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
Out of work	0	10	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
Prefer not to say	0	2	100.0
	1-2	0	0.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
Retired	0	240	92.66
	1-2	18	6.95
	3-5	1	0.39

	5+	0	0.0
	No response	0	0.0
Self-employed (full-time)	0	2	50.0
	1-2	2	50.0
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
Self-employed (part-time)	0	21	95.45
	1-2	1	4.55
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
Student	0	5	71.43
	1-2	2	28.57
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
Unable to work	0	193	89.35
	1-2	21	9.72
	3-5	1	0.46
	5+	1	0.46
	No response	0	0.0
No response	0	0	0.0
	1-2	0	0.0

3-5	0	0.0
5+	0	0.0
No response	0	0.0

Frequency NHS A&E/emergency services were sought by number of dependents.

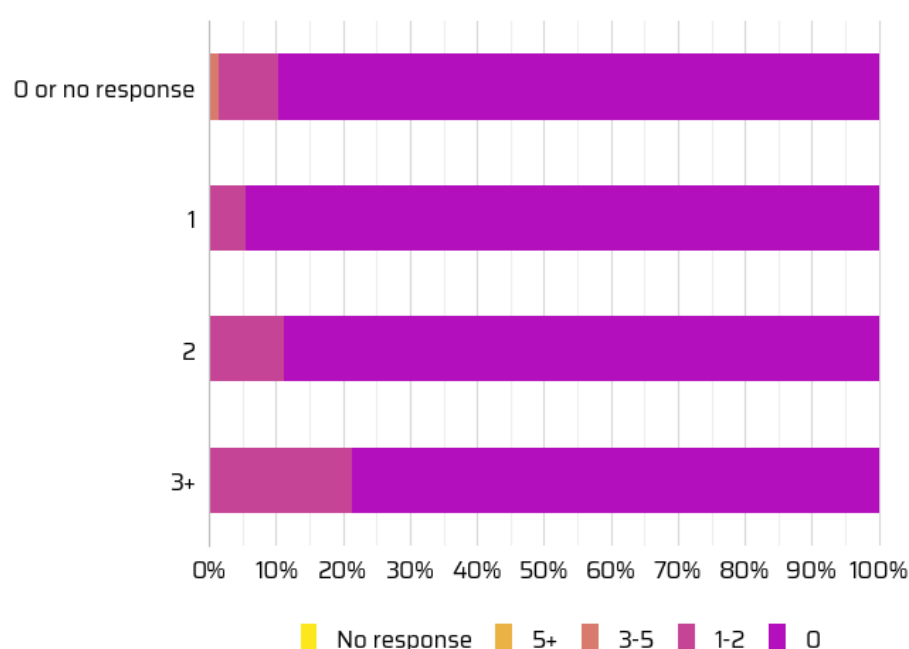


Figure 25: Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Table 25: Frequency that NHS A&E/emergency services were sought, broken down by number of dependents.

Number of dependents	Frequency	Respondents	Percentage
0 or no response	0	458	89.63
	1-2	46	9.0
	3-5	6	1.17
	5+	1	0.2

	No response	0	0.0
1	0	105	94.59
	1-2	6	5.41
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
2	0	32	88.89
	1-2	4	11.11
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0
3+	0	11	78.57
	1-2	3	21.43
	3-5	0	0.0
	5+	0	0.0
	No response	0	0.0

Demographics

Sample size

Total number of respondents: 672

Diagnosis status

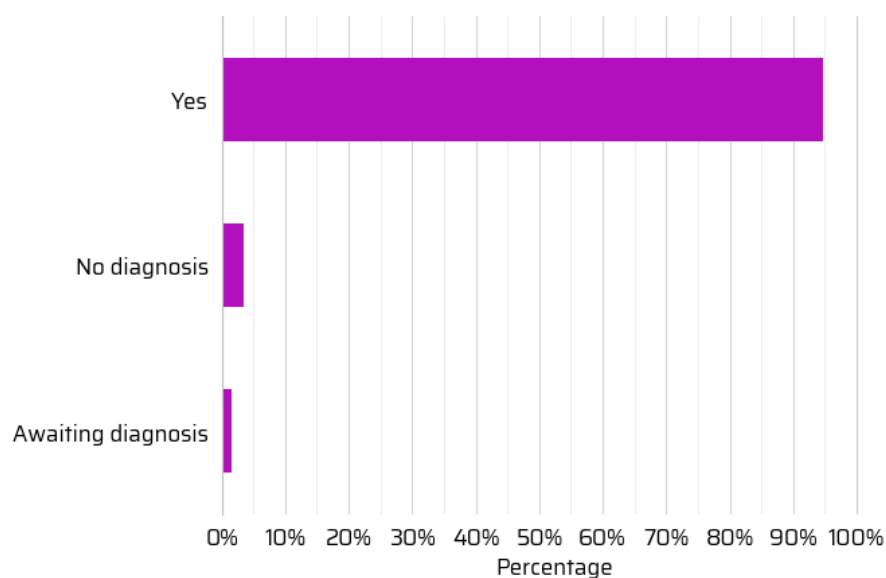


Figure 26: Diagnosis status of the respondents.

Table 26: Diagnosis status of the respondents.

Diagnosis status	Respondents	Percentage
Yes	637	94.79
No diagnosis	24	3.57
Awaiting diagnosis	11	1.64

Diagnosis recency

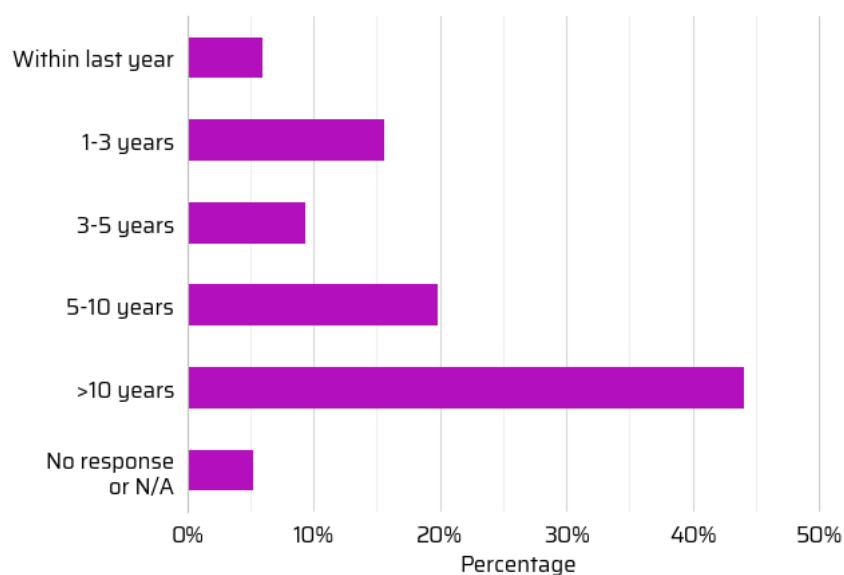


Figure 27: Recency of the respondents' first neurological condition diagnosis.

Table 27: Recency of the respondents' first neurological condition diagnosis

Recency	Respondents	Percentage
Within last year	40	5.95
1-3 years	105	15.62
3-5 years	63	9.38
5-10 years	133	19.79
>10 years	296	44.05
No response or N/A	35	5.21

Location

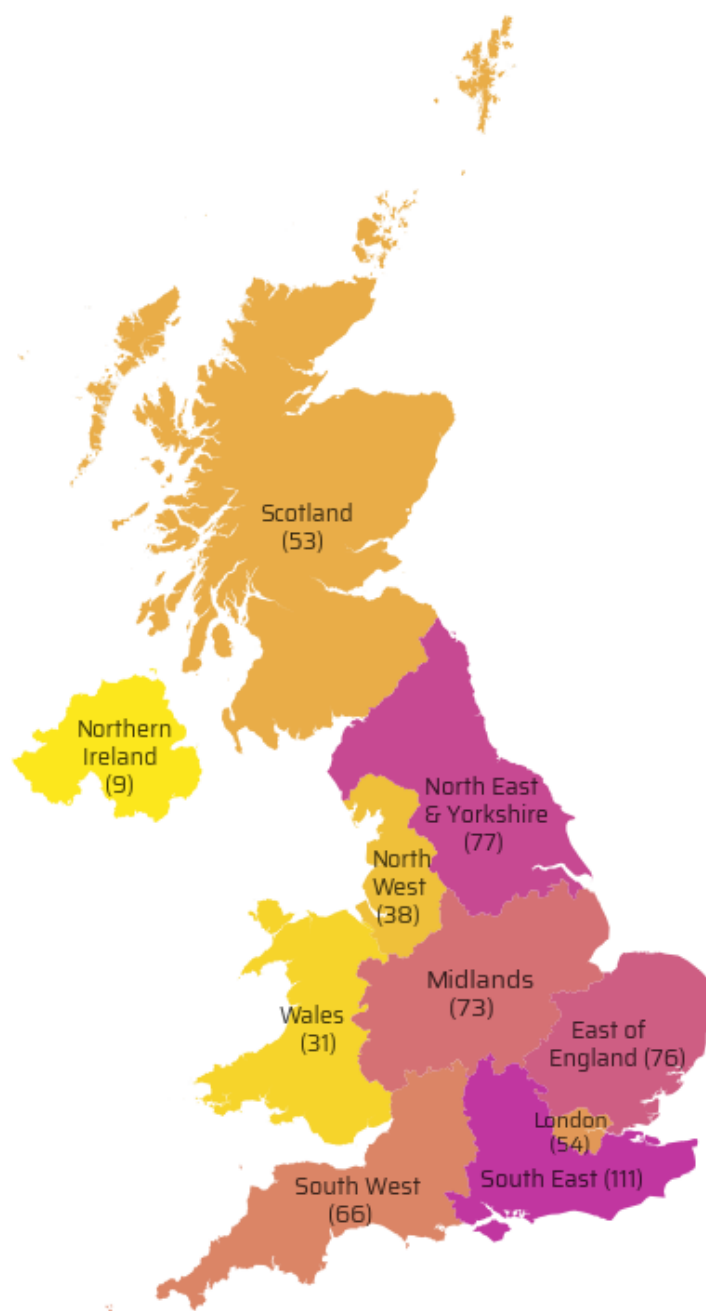


Figure 28: Location of the respondents.

Table 28: Location of the respondents.

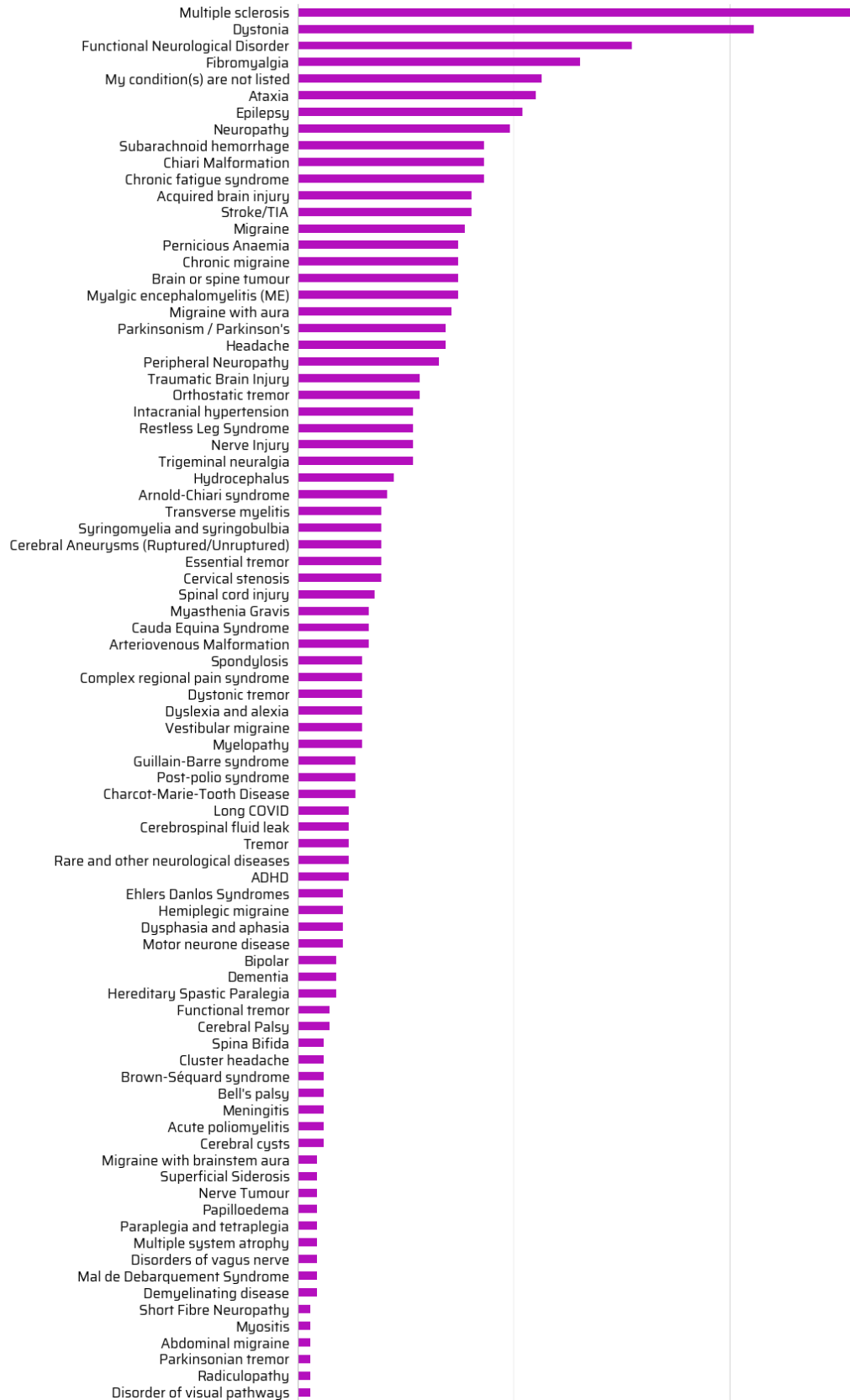
Regions	Respondents	Percentage
South East	111	16.52
North East and Yorkshire	77	11.46
East of England	76	11.31
Midlands	73	10.86
South West	66	9.82
London	54	8.04
Scotland	53	7.89
North West	38	5.65
Wales	31	4.61
Northern Ireland	9	1.34
Isle of Man	3	0.45
Channel Islands	2	0.3
No/invalid response	109	16.22

Note: The regions in England are further divided into 'NHS England Regions'. We asked respondents for the first part of their postcodes. 28 of the respondents have postcodes that span across two or more regions on the map. e.g. some postcodes span across both London and South East, or both Wales and Midlands, etc. Therefore, we do not have the information about which of the two regions these respondents are actually in. For Figure 5 and Table 5, if a postcode spans across two areas, we add 1 to each of these areas. 109 respondents did not provide their postcodes or offered invalid postcodes, and therefore were not included in this analysis.

Neurological conditions

Note: A single respondent may have multiple neurological conditions, so the total number of conditions may not add up to the total number of respondents. The percentages provided indicate the proportion of responses relative to the total number of respondents. 325

respondents (48.36% of the respondents that had answered this question) indicated that they have multiple neurological conditions.



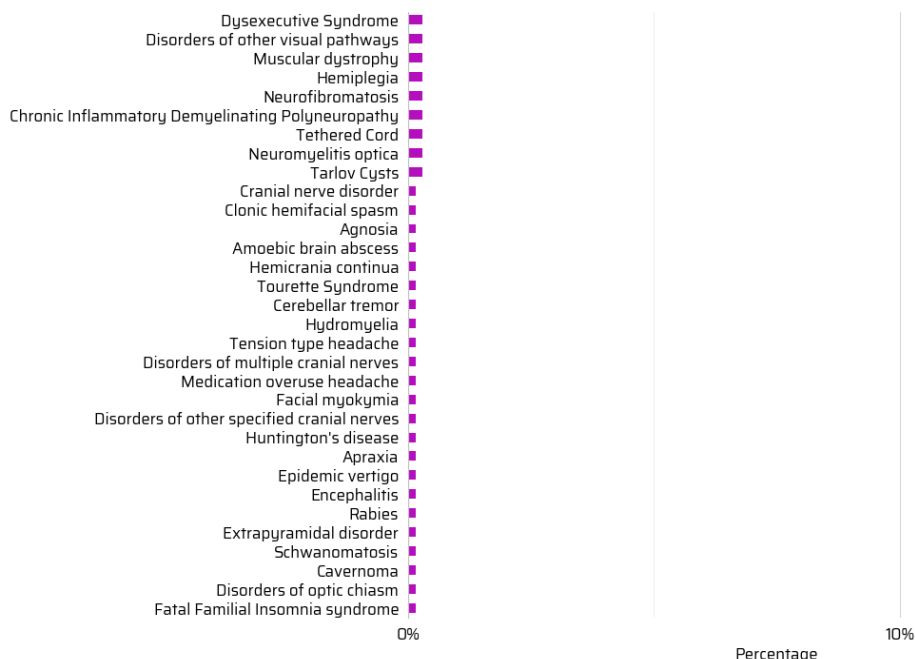


Figure 29: Neurological conditions respondents had been diagnosed with.

Table 29: Neurological conditions respondents had been diagnosed with.

Condition	Respondent s	Percentage
Multiple sclerosis	87	12.95
Dystonia	71	10.57
Functional Neurological Disorder	52	7.74
Fibromyalgia	44	6.55
My condition(s) are not listed	38	5.65
Ataxia	37	5.51
Epilepsy	35	5.21
Neuropathy	33	4.91
Subarachnoid hemorrhage	29	4.32
Chiari Malformation	29	4.32
Chronic fatigue syndrome	29	4.32
Acquired brain injury	27	4.02
Stroke/TIA	27	4.02

Migraine	26	3.87
Pernicious Anaemia	25	3.72
Chronic migraine	25	3.72
Brain or spine tumour	25	3.72
Myalgic encephalomyelitis (ME)	25	3.72
Migraine with aura	24	3.57
Parkinsonism / Parkinson's	23	3.42
Headache	23	3.42
Peripheral Neuropathy	22	3.27
Traumatic Brain Injury	19	2.83
Orthostatic tremor	19	2.83
Trigeminal neuralgia	18	2.68
Intacranial hypertension	18	2.68
Restless Leg Syndrome	18	2.68
Nerve Injury	18	2.68
Hydrocephalus	15	2.23
Arnold-Chiari syndrome	14	2.08
Transverse myelitis	13	1.93
Syringomyelia and syringobulbia	13	1.93
Cerebral Aneurysms (Ruptured/Unruptured)	13	1.93
Essential tremor	13	1.93
Cervical stenosis	13	1.93
Spinal cord injury	12	1.79
Myasthenia Gravis	11	1.64
Cauda Equina Syndrome	11	1.64
Arteriovenous Malformation	11	1.64
Myelopathy	10	1.49

Vestibular migraine	10	1.49
Dyslexia and alexia	10	1.49
Spondylosis	10	1.49
Dystonic tremor	10	1.49
Complex regional pain syndrome	10	1.49
Guillain-Barre syndrome	9	1.34
Post-polio syndrome	9	1.34
Charcot-Marie-Tooth Disease	9	1.34
Long COVID	8	1.19
Cerebrospinal fluid leak	8	1.19
Tremor	8	1.19
Rare and other neurological diseases	8	1.19
ADHD	8	1.19
Hemiplegic migraine	7	1.04
Dysphasia and aphasia	7	1.04
Motor neurone disease	7	1.04
Ehlers Danlos Syndromes	7	1.04
Bipolar	6	0.89
Dementia	6	0.89
Hereditary Spastic Paralegia	6	0.89
Functional tremor	5	0.74
Cerebral Palsy	5	0.74
Spina Bifida	4	0.6
Cluster headache	4	0.6
Brown-Séquard syndrome	4	0.6
Bell's palsy	4	0.6
Meningitis	4	0.6
Acute poliomyelitis	4	0.6

Cerebral cysts	4	0.6
Demyelinating disease	3	0.45
Mal de Debarquement Syndrome	3	0.45
Multiple system atrophy	3	0.45
Disorders of vagus nerve	3	0.45
Migraine with brainstem aura	3	0.45
Paraplegia and tetraplegia	3	0.45
Papilloedema	3	0.45
Nerve Tumour	3	0.45
Superficial Siderosis	3	0.45
Neuromyelitis optica	2	0.3
Tethered Cord	2	0.3
Muscular dystrophy	2	0.3
Chronic Inflammatory Demyelinating Polyneuropathy	2	0.3
Neurofibromatosis	2	0.3
Tarlov Cysts	2	0.3
Hemiplegia	2	0.3
Short Fibre Neuropathy	2	0.3
Disorders of other visual pathways	2	0.3
Dysexecutive Syndrome	2	0.3
Disorder of visual pathways	2	0.3
Radiculopathy	2	0.3
Parkinsonian tremor	2	0.3
Abdominal migraine	2	0.3
Myositis	2	0.3
Disorders of optic chiasm	1	0.15
Cavernoma	1	0.15

Schwanomatosis	1	0.15
Extrapyrarnidal disorder	1	0.15
Rabies	1	0.15
Encephalitis	1	0.15
Epidemic vertigo	1	0.15
Apraxia	1	0.15
Huntington's disease	1	0.15
Disorders of other specified cranial nerves	1	0.15
Disorders of multiple cranial nerves	1	0.15
Medication overuse headache	1	0.15
Clonic hemifacial spasm	1	0.15
Agnosia	1	0.15
Amoebic brain abscess	1	0.15
Hemicrania continua	1	0.15
Cranial nerve disorder	1	0.15
Cerebellar tremor	1	0.15
Hydromyelia	1	0.15
Tourette Syndrome	1	0.15
Tension type headache	1	0.15
Facial myokymia	1	0.15
Fatal Familial Insomnia syndrome	1	0.15

Additional neurological conditions/symptoms.

Respondents were asked to list any neurological conditions/symptoms that they experience that are not listed in the prior questions. Some of the most frequently mentioned ones are as below:

Table 30: Additional neurological conditions/symptoms.

Conditions/Symptoms	Respondents	Other phrasings described by the respondents
Tinnitus	8	
Memory problems	6	"Memory loss", "Problems with remember things"
Spinal stenosis	6	
Progressive supranuclear palsy	4	"PSP"
Autism	4	
Balance problems	4	
Cognitive issues	3	
Fatigue	3	"Neuro fatigue"

Symptoms without diagnosis.

Table 31: Some of the most common symptoms experienced by respondents awaiting diagnosis.

Response	Number	Other phrasing
Headache / head pain	6	"Low pressure headache syndrome", "creeping tentacle like head pain/pressure", "fluish type headache"
Balance problems	6	
Numbness and pins and needles	5	"Lack of use and numbness in limbs", "pins and needles in shoulder, head, lips, tongue, back, chest, arm, bottom, leg, foot", "Pins and needles and bouts of numbness in arms and legs", "numb feeling on rhs of head"
Shoulder and neck pain	5	"pain between shoulder blades", "sore neck"
Fatigue	5	
Back pain	3	"Neurological back pain"

Vision problem	3	“double vision”, “blurred vision”
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Multiple neurological conditions.

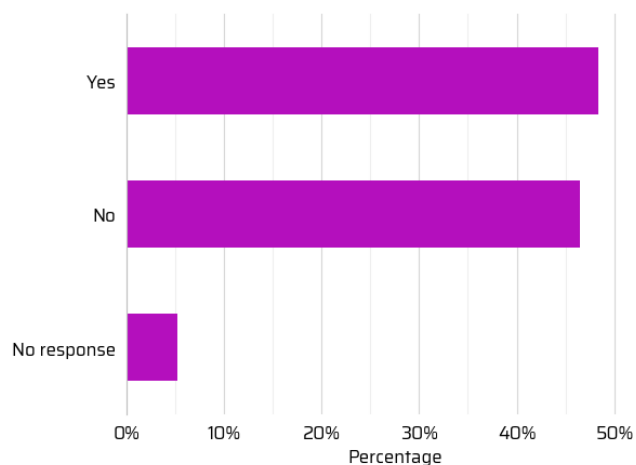


Figure 30: Whether respondents were diagnosed with multiple neurological conditions.

Table 32: Whether respondents were diagnosed with multiple neurological conditions.

Multiple neurological conditions	Respondents	Percentage
Yes	325	48.36
No	312	46.43
No response	35	5.21

Number of non-neurological co-occurring conditions.

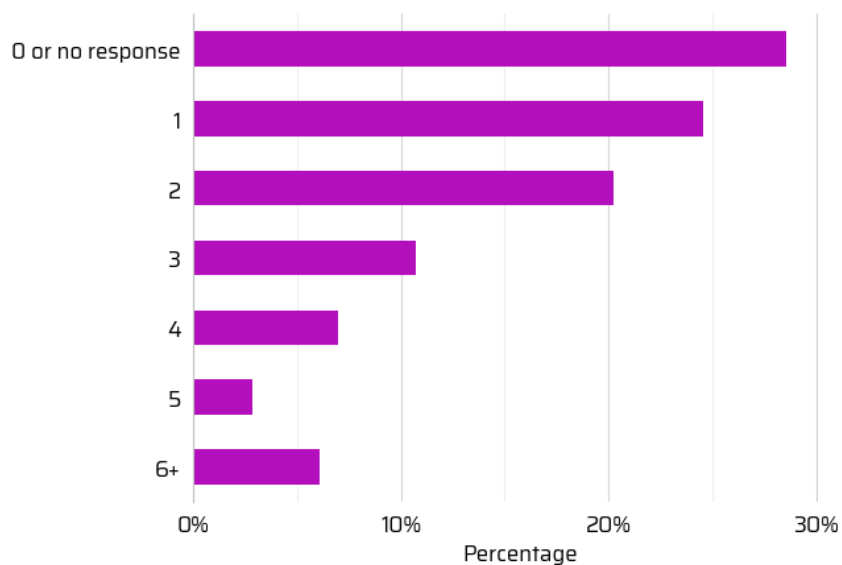


Figure 31: Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s)

Table 33: Number of non-neurological conditions that respondents were diagnosed with that co-occur with their neurological condition(s)

Number of conditions	Respondents	Percentage
0 or no response	192	28.57
1	165	24.55
2	136	20.24
3	72	10.71
4	47	6.99
5	19	2.83
6+	41	6.1

Gender

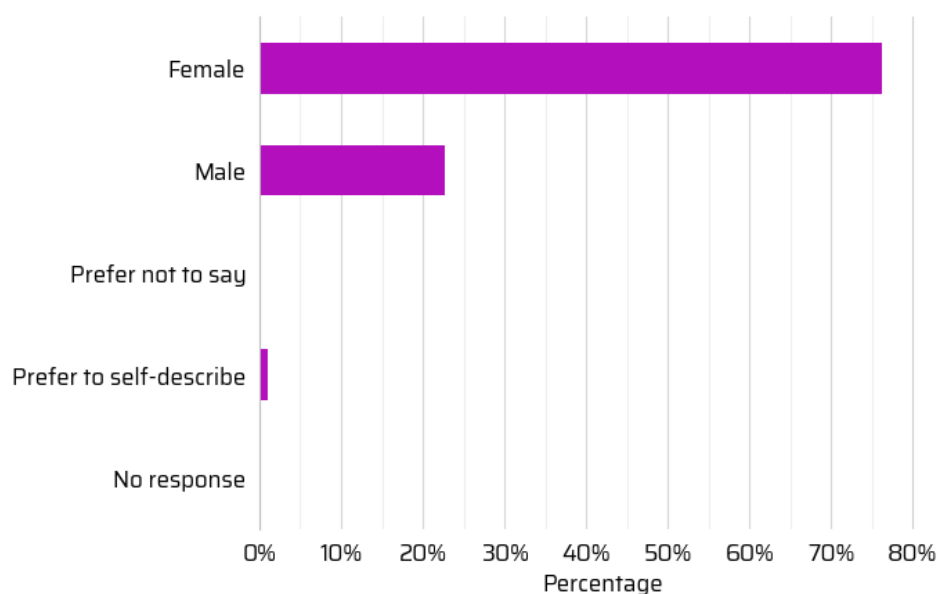


Figure 32: Gender of respondents.

Table 34: Gender of respondents.

Gender	Respondents	Percentage
Female	512	76.19
Male	153	22.77
Prefer not to say	0	0.0
Prefer to self-describe	7	1.04
No response	0	0.0

Sexual orientation

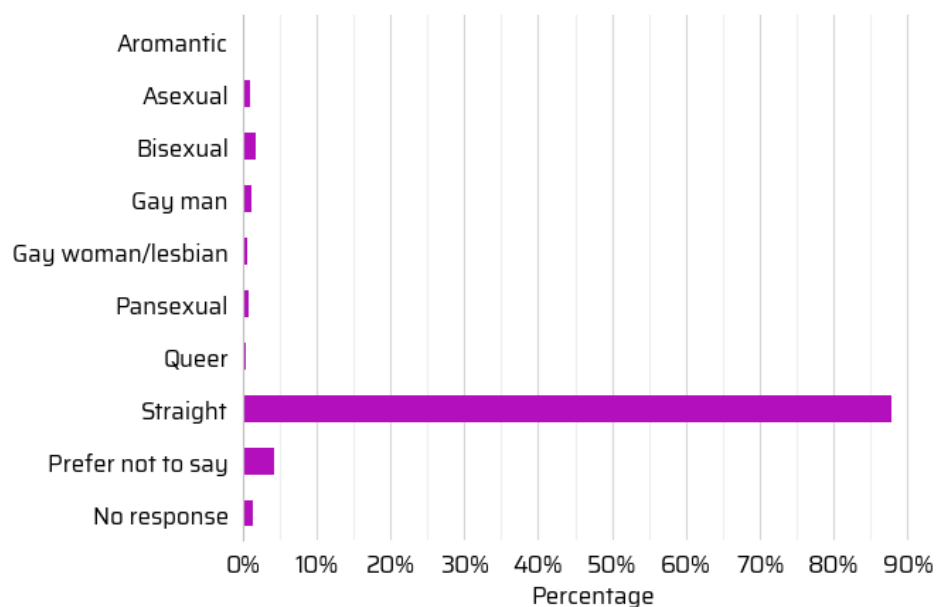


Figure 33: Sexual orientation of respondents.

Table 35: Sexual orientation of respondents.

Sexual orientation	Respondents	Percentage
Aromantic	2	0.3
Asexual	7	1.04
Bisexual	12	1.79
Gay man	8	1.19
Gay woman/lesbian	5	0.74
Pansexual	6	0.89
Queer	3	0.45
Straight	590	87.8
Prefer not to say	29	4.32
No response	10	1.49

Age

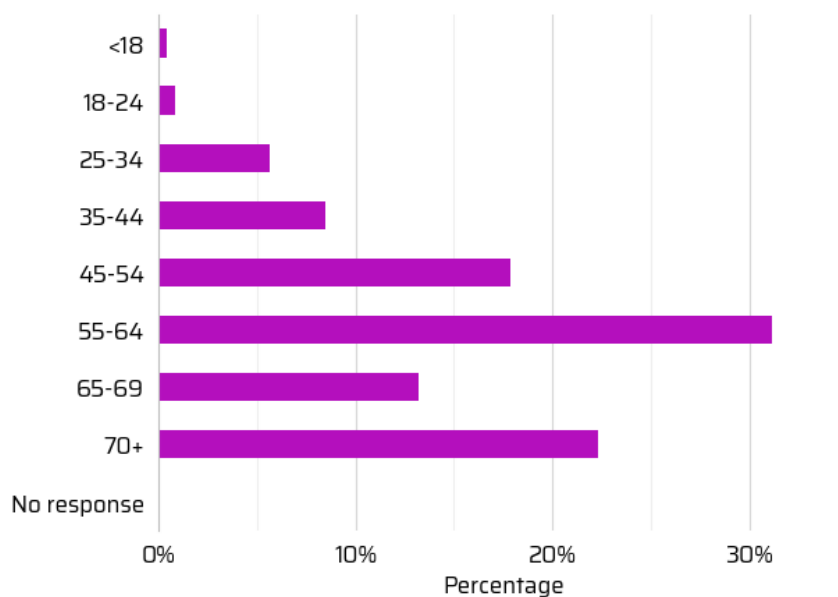


Figure 34: Age of respondents.

Table 36: Age of respondents.

Age	Respondents	Percentage
<18	3	0.45
18-24	6	0.89
25-34	38	5.65
35-44	57	8.48
45-54	120	17.86
55-64	209	31.1
65-69	89	13.24
70+	150	22.32
No response	0	0.0

Employment status

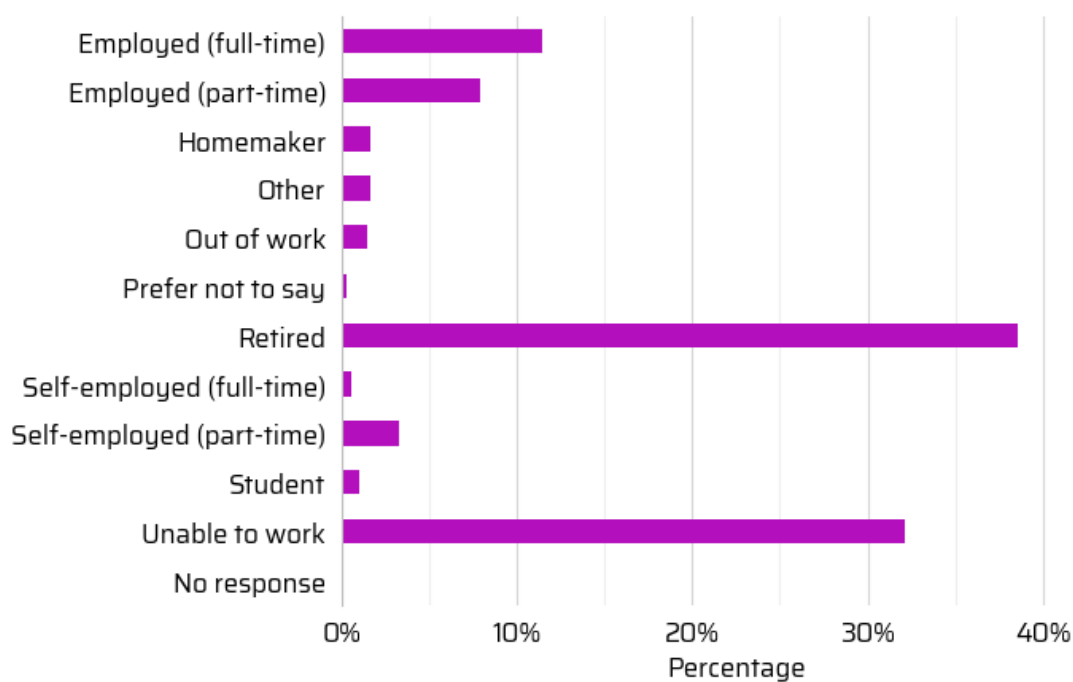


Figure 35: Employment status of respondents.

Table 37: Employment status of respondents.

Employment status	Respondents	Percentage
Employed (full-time)	77	11.46
Employed (part-time)	53	7.89
Homemaker	11	1.64
Other	11	1.64
Out of work	10	1.49
Prefer not to say	2	0.3
Retired	259	38.54
Self-employed (full-time)	4	0.6
Self-employed (part-time)	22	3.27
Student	7	1.04
Unable to work	216	32.14

No response	0	0.0
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Ethnic group

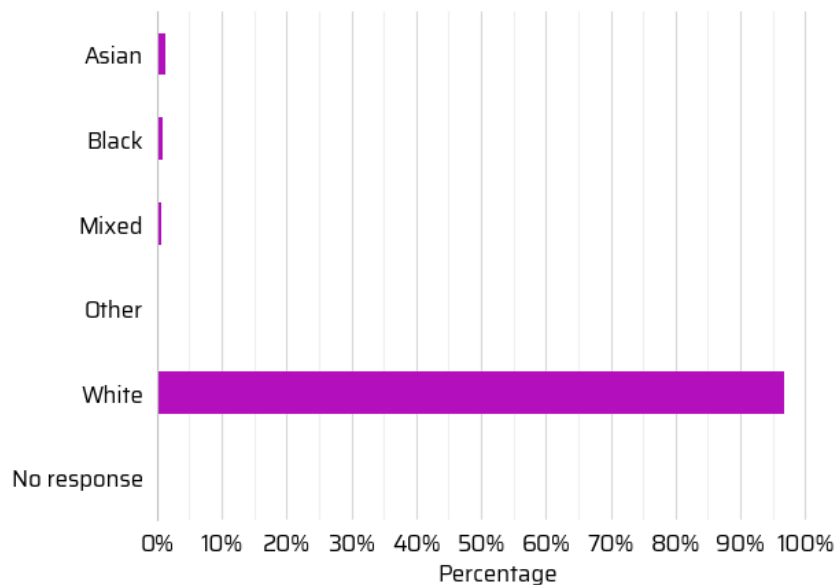


Figure 36: Ethnic group of respondents.

Table 38: Ethnic group of respondents.

Ethnic group	Respondents	Percentage
Asian	9	1.34
Black	6	0.89
Mixed	5	0.74
Other	1	0.15
White	651	96.88
No response	0	0.0

Number of dependents

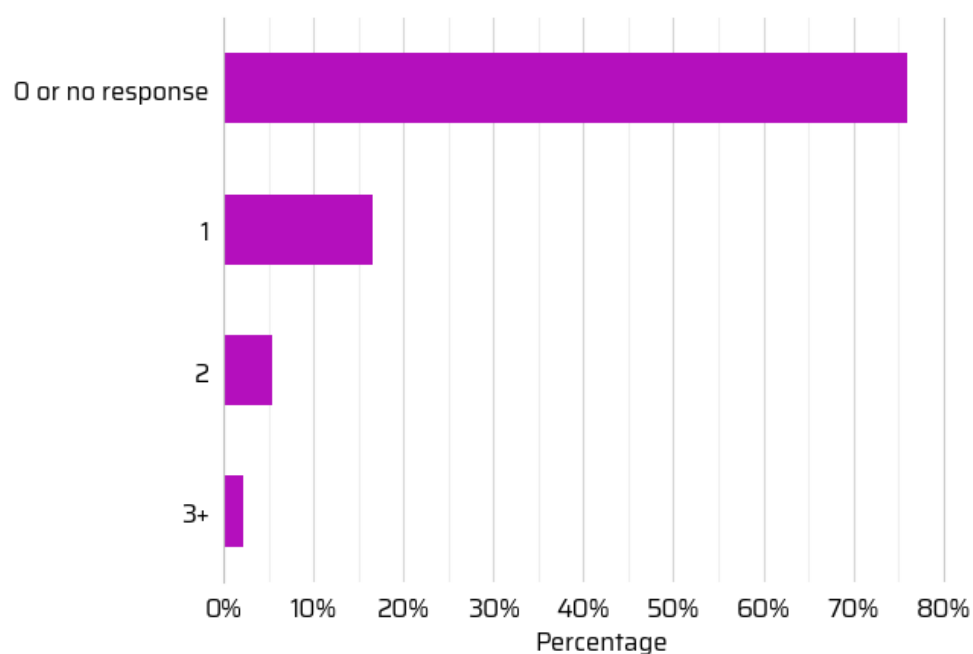


Figure 37: Number of dependents of respondents.

Table 39: Number of dependents of respondents.

Number of dependents	Respondents	Percentage
0 or no response	511	76.04
1	111	16.52
2	36	5.36
3+	14	2.08

Receiving care or support

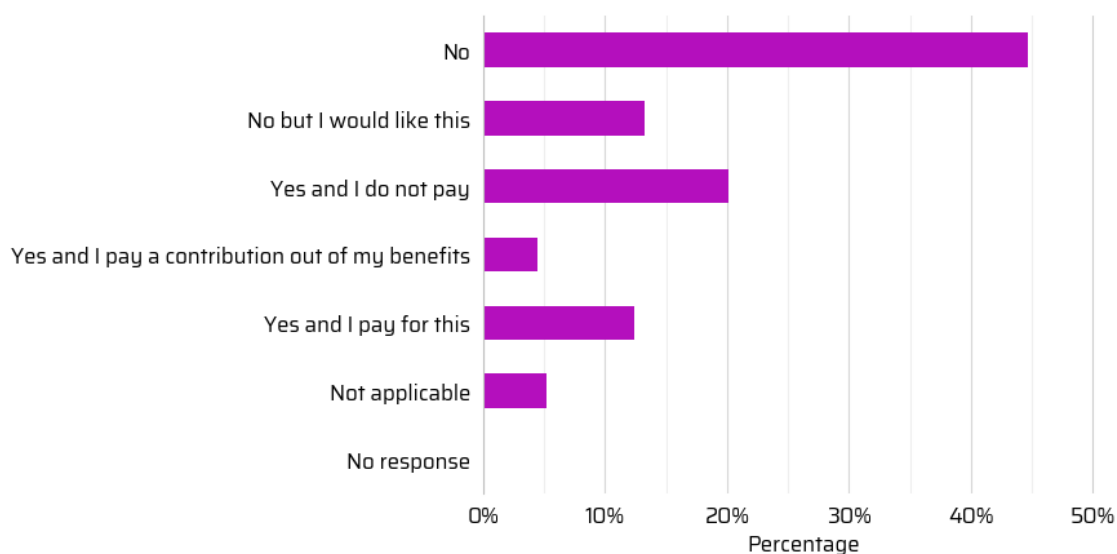


Figure 38: Whether respondents receiving care or support.

Table 40: Whether respondents receiving care or support.

Receive care/support	Respondents	Percentage
No	300	44.64
No but I would like this	89	13.24
Yes and I do not pay	135	20.09
Yes and I pay a contribution out of my benefits	30	4.46
Yes and I pay for this	83	12.35
Not applicable	35	5.21
No response	0	0.0

Appendix A – Survey Questions

Question	Response options		
Are you filling in this questionnaire for yourself?	Yes	No	
About your condition(s) The next few questions are about your neurological condition(s). By sharing your condition(s) and symptoms with us, we can identify variation in care and support. You cannot be identified through the information that you share.			
Have you been diagnosed with a neurological condition(s) or symptom(s)? Please note: Awaiting diagnosis = waiting for the results of a test or a meeting with a specialist to confirm diagnosis. No diagnosis = no medical advice has been sort or a possible diagnosis has not been identified yet.	Yes	Awaiting diagnosis	No diagnosis
As you are either awaiting a diagnosis or do not have one, please share with us the symptoms that you are experiencing. Where possible please list or summarise your symptoms as much as you can.	Free text		
How long has it been since you were diagnosed with your primary neurological condition? If you have multiple conditions the primary condition is the one you feel has the greatest impact on your life.	Within the last year	1-3 years	3-5 years
	5-10 years	Greater than 10 years	
Please tell us which neurological condition you were first diagnosed with. Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'.	See Appendix B for a list of conditions and symptoms		

<p>Do you have any other neurological condition(s) and/or symptoms you would like to add?</p> <p>Please select 'No' if your condition(s) or symptoms was not listed in the previous question.</p>	Yes	No
<p>Please tell us a second neurological condition and/or symptom you have.</p> <p>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'.</p>	See Appendix B for a list of conditions and symptoms	
<p>Do you have any other neurological condition(s) and/or symptoms you would like to add?</p> <p>Please select 'No' if your condition(s) or symptoms was not listed in the previous question.</p>	Yes	No
<p>Please tell us a third neurological condition and/or symptom you have.</p> <p>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'.</p>	See Appendix B for a list of conditions and symptoms	
<p>Do you have any other neurological condition(s) and/or symptoms you would like to add?</p> <p>Please select 'No' if your condition(s) or symptoms was not listed in the previous question.</p>	Yes	No
<p>Please tell us a fourth neurological condition and/or symptom you have.</p> <p>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'.</p>	See Appendix B for a list of conditions and symptoms	
<p>Do you have any other neurological condition(s) and/or symptoms you would like to add?</p> <p>Please select 'No' if your condition(s) or symptoms was not listed in the previous question.</p>	Yes	No
<p>Please tell us a fifth neurological condition and/or symptom you have.</p> <p>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'.</p>	See Appendix B for a list of conditions and symptoms	

<p>Do you have any other neurological condition(s) and/or symptoms you would like to add?</p> <p>Please select 'No' if your condition(s) or symptoms was not listed in the previous question.</p>	Yes		No	
<p>Please tell us a sixth neurological condition and/or symptom you have.</p> <p>Please note if your condition(s) are not listed in the drop down below, there is an opportunity to share them in a subsequent question. If so, please select 'My condition(s) are not listed'.</p>	See Appendix B for a list of conditions and symptoms			
<p>Are there any other neurological conditions or symptoms not listed under the previous question(s) that you would like to make us aware of?</p>	Yes		No	
<p>Please list below any neurological conditions or symptoms that you experience that are not listed in the prior questions.</p> <p>We ask this as it is essential that you feel that NeuroLifeNow accurately represents you and the community of people affected by neurological conditions.</p> <p>Any conditions and symptoms shared here will be considered for inclusion in future surveys.</p>	Free text			
<p>Do you live with conditions other than your neurological condition(s)? If so, how many:</p> <p>This means any other long-term condition which is not neurological. It might include conditions related to your mental health, heart, lungs or joints.</p>	None	1	2	3
	4	5	6+	
<p>About your recent experiences of treatment and support</p> <p>We would like you to rate the quality of care and support services that you have used recently. This includes specialist NHS care, emergency care (e.g. via A&E), social care or support from your GP.</p> <p>These questions are asked in every survey to help us monitor changes over time.</p>				
<p>Have you accessed health or care (from the NHS, a care provider and/or privately) in the past eight weeks?</p>	Yes		No	

Overall, how would you describe your experience of health or care in the last eight weeks?	Very Good		Good		Average	
	Poor		Very Poor		N/A	
How many times have you sought A&E/emergency support from the NHS as a result of your neurological condition in the last eight weeks?	None					
	1-2 times					
	3-5 times					
	5 or more times					
Have you had any medical appointments (including remote appointments) in the last eight weeks?	Yes		No		Don't know	
How many medical appointments have you had in the last eight weeks?	0		1		2	
	4		5		6+	
Who was your first medical appointment with?	Neurologist					
	Specialist Nurse					
	Physiotherapist					
	Speech and Language Therapist					
	Occupational Therapist					
	Psychologist/ Psychiatrist					
	GP					
	Social Services					
	Neurosurgery					
	Diagnostics services (e.g. a radiologist, physiologist)					
	Rehabilitation service					
	Other		Free Text			
How was your first medical appointment delivered?	Phone					
	Videoconference					

	Via text/WhatsApp
	Face to face
	Other Free text
How helpful was your first medical appointment?	It was helpful
	It was not helpful
	Don't Know
Who was your second medical appointment with?	Neurologist
	Specialist Nurse
	Physiotherapist
	Speech and Language Therapist
	Occupational Therapist
	Psychologist/ Psychiatrist
	GP
	Social Services
	Neurosurgery
	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	Other Free text
How was your second medical appointment delivered?	Phone
	Videoconference
	Via text/WhatsApp
	Face to face
	Other Free text
	It was helpful

How helpful was your second medical appointment?	It was not helpful	
	Don't Know	
Who was your third medical appointment with?	Neurologist	
	Specialist Nurse	
	Physiotherapist	
	Speech and Language Therapist	
	Occupational Therapist	
	Psychologist/ Psychiatrist	
	GP	
	Social Services	
	Neurosurgery	
	Diagnostic services (e.g. a radiologist, physiologist)	
	Rehabilitation service	
	Other	Free text
How was your third medical appointment delivered?	Phone	
	Videoconference	
	Via text/WhatsApp	
	Face to face	
	Other	Free text
How helpful was your third medical appointment?	It was helpful	
	It was not helpful	
	Don't Know	
Who was your fourth medical appointment with?	Neurologist	
	Specialist Nurse	

	Physiotherapist
	Speech and Language Therapist
	Occupational Therapist
	Psychologist/ Psychiatrist
	GP
	Social Services
	Neurosurgery
	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	Other Free text
How was your fourth medical appointment delivered?	Phone
	Videoconference
	Via text/WhatsApp
	Face to face
	Other Free text
How helpful was your fourth medical appointment?	It was helpful
	It was not helpful
	Don't Know
Who was your fifth medical appointment with?	Neurologist
	Specialist Nurse
	Physiotherapist
	Speech and Language Therapist
	Occupational Therapist
	Psychologist/ Psychiatrist

	GP
	Social Services
	Neurosurgery
	Diagnostic services (e.g. a radiologist, physiologist)
	Rehabilitation service
	Other Free text
How was your fifth medical appointment delivered?	Phone
	Videoconference
	Via text/WhatsApp
	Face to face
	Other Free text
How helpful was your fifth medical appointment?	It was helpful
	It was not helpful
	Don't Know
Who was your sixth medical appointment with?	Neurologist
	Specialist Nurse
	Physiotherapist
	Speech and Language Therapist
	Occupational Therapist
	Psychologist/ Psychiatrist
	GP
	Social Services
	Neurosurgery
	Diagnostic services (e.g. a radiologist, physiologist)

	Rehabilitation service
	Other Free text
How was your sixth medical appointment delivered?	Phone
	Videoconference
	Via text/WhatsApp
	Face to face
	Other Free text
How helpful was your sixth medical appointment?	It was helpful
	It was not helpful
	Don't Know
To what extent do you feel your mental wellbeing needs are being met?	To a great extent
	To a moderate extent
	To a small extent
	Not at all
	Don't Know
Quality of life and wellbeing We know that having a neurological condition(s) affect all aspects of a person's life. These next questions look to capture how your life and wellbeing are affected.	
Which of the following describes how you feel at the moment? Please select all that apply.	Calm
	Well supported
	Anxious
	Hopeless
	Lonely
	Other Free text

What other words would you use to describe how you feel at the moment?	Free text
To what extent is your quality of life affected by your neurological condition?	To a great extent
	To a large extent
	Somewhat
	A little
	Not at all
About you The following questions help us to identify any potential variation in the daily realities, care, and support, while also aiding us in striving to be as representative as possible.	
What is your age range?	Under 18 years of age
	18 to 24 years of age
	25 to 34 years of age
	35 to 44 years of age
	45 to 54 years of age
	55 to 64 years of age
	65 to 69 years of age
	Over 70 years of age
To which of these ethnic groups do you belong?	White British
	White Irish
	Any other White background
	White and Black Caribbean
	White and Asian
	Any other mixed background
	Indian

	Pakistani
	Bangladeshi
	Any other Asian background
	Caribbean
	African
	Any other Black background
	Chinese
	Any other ethnic background
What is your gender?	Male
	Female
	Prefer to self-describe
	Prefer not to say
What is your sexual orientation?	Aromantic
	Asexual
	Bisexual
	Gay man
	Gay woman/lesbian
	Pansexual
	Queer
	Straight (heterosexual)
	Prefer not to say
	Other Free text
What best describes your employment status?	Employed (full time)
	Employed (part time)

	Self-employed (full-time)			
	Self-employed (part-time)			
	Homemaker			
	Student			
	Out of work			
	Unable to work			
	Retired			
	Prefer not to say			
	Other		Free text	
How many dependents live with you?	1	2	3	4
	5	6+		
Do you receive any care or support at home for your day-to-day life?	Yes and I pay for this			
	Yes and I pay a contribution out of my benefits			
	Yes and I do not pay			
	No but I would like this			
	No			
	Not applicable			
Communicating with you. <p>If you are happy to hear from us about how your support is benefitting people affected by neurological conditions, please complete the following questions. You can stop receiving communications or change any of your preferences at any time by contacting us at: info@neurolifenow.org. For full details of what information, we hold and how we process your data, please see our privacy policy.</p>				
What is your first name?		Free text		
Your name will only be used for communications purposes.				
They will not be used as part of the research or shared with third parties.				

<p>What is your surname?</p> <p>Your name will only be used for communications purposes.</p> <p>They will not be used as part of the research or shared with third parties.</p>	Free text
<p>What is your Email Address?</p> <p>Your email will only be used for communications purposes.</p> <p>It will not be used as part of the research or shared with third parties.</p>	Free text
<p>What is the first line of your address?</p> <p>Your address will only be used for communications purposes. It will not be used as part of the research or shared with third parties.</p>	Free text
<p>The first part of your postcode?</p> <p>i.e. E1, HP15, L1, EC1, etc</p> <p>The first part of your post code is used in the research to identify differences in experience depending on where people live in the UK, while also allowing us to monitor if we are reaching people from all over the UK.</p> <p>It is also used for communication purposes.</p>	Free text
<p>What is the second part of your postcode?</p> <p>The second part of your postcode will be combined with the first part and used for communications only.</p> <p>It will not be used as part of the research or shared with third parties.</p>	Free text

Appendix B – List of conditions

Abdominal migraine	Acquired brain injury	Acute poliomyelitis
ADHD	Agnosia	Amoebic brain abscess
Apraxia	Arnold-Chiari syndrome	Arteriovenous Malformation
Ataxia	Bell's palsy	Bipolar
Brain or spine tumour	Brown-Séquard syndrome	Cauda Equina Syndrome
Cavernoma	Central Pontine Myelinolysis	Cerebellar tremor
Cerebral Aneurysms (Ruptured/Unruptured)	Cerebral cysts	Cerebral Palsy
Cerebrospinal fluid leak	Cervical stenosis	Chagas' disease
Charcot-Marie-Tooth Disease	Chiari Malformation	Chronic fatigue syndrome
Chronic Inflammatory Demyelinating Polyneuropathy	Chronic migraine	Clonic hemifacial spasm
Cluster headache	Complex regional pain syndrome	Cranial nerve disorder
Creutzfeldt-Jakob disease	Cyclical vomiting syndrome	Cysticercosis of central nervous system
Dementia	Demyelinating disease	Disorder of visual pathways
Disorders of hypoglossal nerve	Disorders of multiple cranial nerves	Disorders of olfactory nerve
Disorders of optic chiasm	Disorders of other specified cranial nerves	Disorders of other visual pathways
Disorders of vagus nerve	Disorders of visual cortex	Down's Syndrome
Dysarthria and anarthria	Dysexecutive Syndrome	Dyslexia and alexia
Dysphasia and aphasia	Dystonia	Dystonic tremor
Eaton-Lambert syndrome	Ehlers Danlos Syndromes	Encephalitis
Enhanced physiologic tremor	Epidemic vertigo	Epilepsy
Essential tremor	Extradural and subdural abscess	Extrapyramidal disorder
Facial myokymia	Faetal Alcohol Spectrum Disorders (FASD)	Fatal Familial Insomnia syndrome
Fibromyalgia	Functional Neurological Disorder	Functional tremor
Geniculate ganglionitis	Guillain-Barre syndrome	Headache

Headache	Headache associated with exercise	Hemicrania continua
Hemicranial Corrina	Hemiplegia	Hemiplegic migraine
Hereditary Spastic Paralegia	High altitude headache	Huntington's disease
Hydrocephalus	Hydromyelia	Hypnic headache
Intacranial hypertension	Intracranial abscess and granuloma	Intracranial and intraspinal abscess and granuloma in diseases classified elsewhere
Intracranial and intraspinal phlebitis and thrombophlebitis	Intraspinal abscess and granuloma	Kennedy's disease
Leukoencephalitis	Long COVID	Mal de Debarquement Syndrome
Malaria	Medication overuse headache	Melkersson's syndrome
Meningeal tuberculoma	Meningitis	Menstrual migraine
Migraine	Migraine with aura	Migraine with brainstem aura
Migraine without aura	Motor neurone disease	Multiple sclerosis
Multiple system atrophy	Muscular dystrophy	My condition(s) are not listed
Myalgic encephalomyelitis (ME)	Myasthenia Gravis	Mycoses
Myelopathy	Myopathy	Myositis
Myotonic disorders	Narcolepsy and cataplexy	Nerve Injury
Nerve palsy	Nerve Tumour	Neurofibromatosis
Neuromyelitis optica	Neuropathy	Neurosarcoidosis
Optic atrophy	Orthostatic tremor	Papilloedema
Paraplegia and tetraplegia	Parkinsonian tremor	Parkinsonism / Parkinson's
Peripheral Neuropathy	Pernicious Anaemia	Post-polio syndrome
Postzoster neuralgia	Progressive multifocal leukoencephalopathy	Rabies
Radiculopathy	Rare and other neurological diseases	Refsum's Disease
Restless Leg Syndrome	Schwanomatosis	Short Fibre Neuropathy
Spina Bifida	Spinal cord injury	Spinal muscular atrophy
Split Cord	Spondylosis	Stroke/TIA

Subacute sclerosing panencephalitis	Subarachnoid hemorrhage	Superficial Siderosis
Syringomyelia and syringobulbia	Tarlov Cysts	Tension type headache
Tethered Cord	Tourette Syndrome	Toxic encephalopathy
Toxoplasma meningoencephalitis	Transverse myelitis	Traumatic Brain Injury
Tremor	Trigeminal neuralgia	Tuberculous meningitis
Vascular myelopathies	Vestibular migraine	